

Comparison of Multiple Sclerosis clients´ subjective self-reports and objective walking tests

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<p>Det här slutarbetet var ett beställningsarbete av öppenrehabiliteringsenheten Aksoni. Öppenrehabiliteringsenheten Aksoni erbjuder personer med Multippel Skleros samt personer med andra sällsynta neurologiska sjukdomar olika tjänster bl.a. läkarmottagning, rehabilitering samt sociala tjänster.</p> <p>Primära ändamålet är att studera vilka relationer kan observeras när man evaluerar en MS klient med subjektiva och objektiva gång mätinstrument. Sekundära målet är att undersöka vilka möjliga relationer kan observeras mellan uppsatta mål, volym av rehabilitering, intryck av förändring samt det objektivt mätta gången. För att svara på forskningsfrågorna användes jämförande fallstudie som metod samt statistiska räkningar användes sedan för att stärka och verifiera resultaten.</p> <p>Inkluderade klienter hade en definitiv MS diagnos samt en <i>Expanded Disability Status Scale</i> (EDSS) - mätinstrument grad ställd av en neurolog under eller lika med 6.5. Klienter blev exkluderade ifall de hade någon annan diagnos som kunde inverka på personens gångförmåga. Alla klienter medgav skriftligt godkännande. Denna studie godkändes av den etiska kommittéen i Egentliga Finlands sjukvårdsdistrikt. Studien började med de preliminära mätningarna, basmätningarna, hösten 2011 i Aksoni rehabiliteringsenheten. Följande mätningar skedde 2-3 månader senare (Test 1) och de sista mätningarna gjordes 9-12 månader från basmätningarna (Test2).</p> <p>Resultaten visar starka korrelationssamband mellan gångtesterna. Samt relaterar de subjektiva mätinstrumenten med varandra. Resultaten i studien kom an genom analysen i den jämförande fallstudien samt genom statistiska räkningar. De viktigaste slutsatserna i var att de subjektiva och objektiva mätinstrumenten motsatte sig varandra. Till största delen bekräftades detta i den statistiska analysen. Den statistiska analysen visade dock ett samband mellan gångförmågans förutsägbarhet och den subjektiva mätaren MSWS-12 när den visade sig korrelera med den objektiva gångmätaren på 6 minuter.</p> <p>Tolkningen av rehabiliteringen var bred och inkluderade många olika former av rehabilitering (individuell, grupp och självständig). Alla dessa fungerar och inverkar olika på individen och själva processen. Mer specificitet krävs för framgångsrik forskning i området.</p>	
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<p>Tämä opinnäytetyö on Avokuntoutus Aksonin tilaama. Avokuntoutus Aksoni tarjoaa Helsingissä keskushermoston pesäkekovettumatautia (MS) ja eteneviä harvinaisia neurologisia sairauksia (harnes) sairastavien ja heidän läheistensä hyväksi erilaisia palveluja, joihin kuuluu neurologin ja sosionomin vastaanotot sekä kuntoutuspalveluja eri muodoissa.</p> <p>Tämän opinnäytetyön primääri tavoite oli tutkia, mitä yhteyksiä on havaittavissa, kun MS-asiakasta arvioidaan subjektiivisilla mittareilla ja objektiivisilla kävelymittareilla. Sekundäärisenä tavoitteena tutkittiin, onko asetettujen tavoitteiden, kuntoutusmäärän, kuntoutujan oman näkemyksen muutoksesta ja objektiivisesti mitattujen kävelytulosten välillä löydettävissä yhteyksiä. Tutkimuskysymysten analysoimiseksi käytettiin vertailevaa tapaustutkimusmetodia, ja löydösten vahvistamiseksi käytettiin tilastollisia laskelmia. Tutkimukseen otetut asiakkaat olivat saaneet definiivisen pesäkekovettumataudin diagnoosin sekä <i>Expanded Disability Status Scale</i> -mittarilla tuloksen 6.5 tai alle neurologin päättämänä. Tutkimuksesta poissuljettiin kaikki sellaiset asiakkaat, joilla oli muu lääketieteellinen diagnoosi, joka saattaisi vaikuttaa kävelykykyyn. Kaikki tutkimukseen sisällytetyt asiakkaat allekirjoittivat kirjallisen suostumuksen, ja Varsinais-Suomen sairaanhoitopiirin eettinen toimikunta hyväksyi tämän tutkimuksen aloittamisen. Tutkimus alkoi Avokuntoutus Aksonissa syksyllä 2011 ja seuraava mittaus suoritettiin tästä 2-3 kuukautta myöhemmin (Testi 1). Viimeinen mittaus tehtiin 9-12 kk päästä ensimmäisestä mittauksesta (Testi 2).</p> <p>Tutkimustulokset osoittavat vahvaa korrelaatiota kävelymittareiden välillä sekä yhteyksiä subjektiivisten mittareiden välillä. Tulokset kartoitettiin vertailevan tapaustutkimuksen ja tilastollisten laskelmien avulla. Päätulos vertailevassa tapaustutkimuksessa oli löydös subjektiivisten ja objektiivisten mittareiden vastakohtaisuudesta. Tilastolliset laskelmat ovat suurelta osin vahvistaneet nämä löydökset. Lisäksi tilastolliset laskelmat osoittivat, että subjektiivinen kyselylomake MSWS-12 korreloi objektiivisen 6 minuutin kävelytestin kanssa ja voi täten jossain määrin ennustaa kävelykykyä.</p> <p>Kuntoutuksen tulkinta oli tässä tutkimuksessa laaja, sisältäen sekä yksilö-, ryhmä-, että itsenäistä kuntoutusta. Kaikki nämä kuntoutusmuodot vaikuttavat eri tavalla. Kuntoutuksen tarkempaa määrittelyä kaivataan jatkossa tarkempien löydösten saavuttamiseksi.</p>	
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<p>This study was commissioned by the Outpatient Rehabilitation Center Aksoni in Helsinki. Aksoni offers services to persons with Multiple Sclerosis, clients with other rare progressive neurological diseases and the families of these groups. Services include doctors' appointments, rehabilitation and social services.</p> <p>The primary objective of this study was to establish what relations can be found when using subjective self-report measures and objective performance based walking tests to evaluate MS clients. The secondary objective was to study what relations can be found between set goals, volume of rehabilitation, clients' impression of change and the objectively measured walking capacity. To answer these questions a comparative case study research method was used, statistical calculations were used to strengthen and verify the results of the analysis. Included clients had a definite diagnosis of MS, an <i>Expanded Disability Status Scale</i> (EDSS) score below or equal to 6.5 as determined by neurologists. Clients were excluded if they had other medical conditions interfering with walking. All provided written informed consent. This study was approved in Proper Finland by the local health care districts ethical committee.</p> <p>The study started in Aksoni center in the fall 2011 with baseline testing. The next measurements were conducted 2-3 months later (Test 1) and the third and last measurements were concluded 9 months to one year from the baseline measurements (Test 2).</p> <p>Objective measures presented here correlate well with each other. Similarly, the subjective measures relate with each other. These results were found by the comparative case study analysis as well as statistical analysis. The main finding of the comparative analysis was that results from subjective and objective measures differ significantly. For the most part, this is verified by statistical analysis. However, it showed that the subjective self-report measure MSWS-12 correlate with the objective walk test of 6min and can therefore predict walking ability to some extent.</p> <p>The interpretation of rehabilitation was wide in this study and included many different forms of rehabilitation (single, group and autonomous rehabilitation) all which work and affect the rehabilitation process very differently. More specificity is needed in future research.</p>	
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Foreword

This thesis started with a dream. I was attending a RIMS congress in Turku and there was prof. Dr Peter Feys giving a speech about their international research and welcoming anybody interested to join them. I found the prospect of being a part of something so interesting most fascinating. That was the beginning of a journey which led me to Barcelona and also made me a part of that international research team. Research questions started to rise in this process also from within my own workplace leading to this thesis to be commissioned. With the help and guidance from Anders Romberg, Annika Ingves and the support from Nina Henrikssen and of course all of the staff in Outpatient Rehabilitation Center Aksoni and the Finnish Neuro Society I could commit to both the international research and the work in this thesis, that I find so important and close to my heart. I also wish to thank my school Arcada, University of Applied Sciences, my teacher Ira Jeglinsky-Kankainen and all of the participating clients who believed in me and gave me their valuable time and effort.

Most importantly I wish to thank my daily source of inspiration, my beloved husband Arttu and daughter Ellen who make everything worthwhile.

Thank you.

Espoo, June, 2015

Johanna Meriläinen

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1 INTRODUCTION

This study is a continuum to a Multicenter Trial designed and led by Prof. Dr. Peter Feys and is conducted within the European Rehabilitation in Multiple Sclerosis (RIMS) organization. (Feys et al. 2012 p. 2)

The RIMS (Rehabilitation in Multiple Sclerosis) organization is a European network of health care professionals working with Multiple Sclerosis (MS), especially researchers and health care professionals working with clients who have Multiple Sclerosis. The organization consists of professionals at different MS centers as well as individual health care professionals working elsewhere. The goal of this non-profit organization is scientific, with a special interest to enhance evidence based rehabilitation of people with MS. (RIMS brochure 2014, [www](#))

The primary research objective of the Multicenter Trial was to “compare the internal and external responsiveness of short versus long walk tests”. The secondary research objective is to “examine the differential impact of diverse physical rehabilitation programs on walking capacity”. The data on walking capacity is gathered from clinical and research centers in different European countries. (Feys et al. 2012 p. 5)

One such institution is the Finnish Neuro Society which is a non-profit, public service organization that looks after its Finnish members with MS, clients with other rare progressive neurological diseases and the families of these groups. The aim of the organization is to promote research in the field of neurological diseases, provide nursing and rehabilitation and look after their clients’ social benefits as well as provide information to the general public and students (The Finnish MS Society, 2014, [www](#)). The Finnish Neuro Society is considered to be part of the third sector (Heikkilä et al. 2013 p. 4).

This study was commissioned by the Outpatient Rehabilitation Center Aksoni in Helsinki that is part of the Finnish Neuro Society. One of Aksoni’s goals is to offer its clients a versatile, evidence based and an individually planned rehabilitation (Aksoni, 2015, [www](#)). Evaluating the clients with the appropriate measurements is important for the rehabilitation process to be successful. This thesis was commissioned with this in

mind. Also according to Finnish law (KKRL 566/2005 10 §) rehabilitation is found on evidence based practices (Paltamaa et al. 2011 p. 35 – 38).

2 THEORETICAL FRAMEWORK

Neurological rehabilitation is seen more and more as a journey where the starting point and goal must be defined by the client in co-operation with a therapist. The client is seen as a partner and their own contribution to the rehabilitation process is as important as that of professionals (Kettunen et al. 2002 p. 9). Comparing subjective measurements to walking capacity is a natural choice, as Baert et al. (2014 p.1) state in the introduction to the Multicenter study by referring to the studies made by Hobart et al. (2001) and Larocca (2011). Here it was observed that walking ability was the highest ranked and most valued bodily function for people with MS.

Among others, the following key words were used for the literary review: multiple sclerosis, subjectivity, cognition, perception, balance, walking, gait, physical activity, EDSS, rehabilitation, empowerment and chronic illness. Research databases included: CINHALL, Academic Search Elite and Science Direct. Research older than ten years was excluded, with a few exceptions, from the theoretical framework.

2.1 Multiple Sclerosis

Information conduction in the human body is enabled by neuroendocrine glands which secrete chemical messages to control body functions and the nervous system that at a cellular level consists of neurons. Neurons send signals, information, to other cells. The signals are in the form of electrochemical waves traveling along thin fibers called axons. At intersections (synapses) neurotransmitters are freed. Interconnected neurons form neural networks that together in co-operation with the neuroendocrine glands form our information highway. It has been documented that these two systems both influence each other and work in symbiosis. (Soinila et al. 2006 p. 12, 57)

MS is the result of a progressive neurodegeneration (Huisinga et al. 2013 p. 303). Autoimmunity is compromised and the body is attacking itself by damaging myelin and oligodendrocytes. Myelin forms a protective sheath that covers the axon (Rautiainen &

Tienari in: Soynila et al.2006 p. 380). Oligodendrocytes provide support and insulation to axons in the brain (Rautiainen & Tienari in: Soynila et al. 2006 p. 56). This results in nerve fiber damage and slows down or totally cuts off the axonal conduction. (White & Dressendorfer 2004 p. 1079)

The human body is able to repair damages done to the myelin sheath or oligodendrocytes support but not to the axon itself. If undamaged, the axon can grow new shoots. This explains why in MS the symptoms can first appear worse and then slowly diminish totally or partly depending on the scale of the damage (Rautiainen & Tienari in: Soynila et al. 2006 p. 57, 379, 380-381). Permanent nerve damage can lead to significant versatile problems as the damage can occur in motor and sensory tracts or in proprioceptive, visual and vestibular pathways (White & Dressendorfer 2004 p. 1079).

Multiple Sclerosis is a disease that can progress in very different patterns, which are described in Table 1. Relapses often occur after an infection in the body activating the immune system. (Rautiainen & Tienari in: Soynila et al. 2006 p. 385-386)

Table 1. Types of Multiple Sclerosis (Rautiainen & Tienari in: Soynila et al. 2006 p. 385-386).

Relapsing-remitting MS is characterized by relapses (0.1 – 1 per year) followed by periods of either total or partial recovery.

Secondary progressive MS occurs with initial relapsing-remitting MS, but eventually progresses to a steady neurologic decline between relapses without any definite periods of remission.

Progressive relapsing MS is from onset a steady progressive decline but also clear relapses occur. This is the least common of all subtypes.

Primary progressive MS occurs with no remission after the initial symptoms. It is characterized by progression of disability from onset, with no remissions and improvements.

2.1.1 Expanded Disability Status Scale (EDSS)

MS is most often evaluated with the Expanded Disability Status Scale (EDSS), which is a numerical approach of the person's physical abilities (Pugliatti et al. 2008 p. 158). The starting point of this measurement tool was in 1955 when John F. Kurtzke introduced the DSS scale (Disability Status Scale) which for the first time could be used to define the disability status of people with MS. Neurologic deficits were evaluated in a

neurological examination. Later the FS system was developed to be used with DSS. FS stands for Functional Systems and today it consists of

- Pyramidal functions
- Cerebellar functions
- Brainstem functions
- Sensory functions
- Bowel and bladder functions
- Visual functions
- Cerebral functions

Since DSS was insensitive to change in the middle of the scale range, Kurtzke introduced the Expanded Disability Status Scale. EDSS definitions are listed in *Appendix 6* EDSS relies even more heavily on the standard neurologic examination as encoded in FS. In fact, in the bottom range the EDSS score relies solely on the FS grade. (Kurtzke 1983 p. 1444-1445)

EDSS has received criticism but it is still the most widely used and known measurement in clinical trials. By definition, it must fulfill clinical and scientific criteria, it must be applicable to all patients and it should be user friendly. Since the 1990s EDSS and FS have been tested and validated with varying results. EDSS and FS measure overall disability and discriminate disability from other health issues. They show good inter-rater reproducibility, poor responsiveness and have limited ability to discriminate between people and groups. (Hobart et al. 2000 p. 1027-1035) Romberg (2013 p. 52), when referring to Kragt et al. (2006), even states it has been considered the “golden standard for measuring disability in MS”. Romberg (2013 p. 67) also points out in his own study that neurological disability evaluated with EDSS was shown to be a predictor of exercise capacity in MS.

2.2 Physical activity of persons with MS

Physical activity for a person with MS is challenged by many different factors. The nature of the disease is debilitating. Statistically, 15 years after diagnosis 50% require assistance when walking and 10% require a wheelchair to move around (Kellher et al. 2010 p. 1242).

Fatigue is a common symptom 65% report having, fatigue being defined as a “systemic feeling of tiredness” (White & Dressendorfer 2004 p. 1077). For some persons with MS, fatigue is the most debilitating symptom affecting everyday living and working

(Rautiainen and Tienari in: Soynila et al. 2006 p. 387-388). Spastic paresis, an upper motor neuron impairment causing exaggerated reflexes and muscle weakness, is also common. Problems occur also with balance as a result of problems with the visual, sensory and vestibular pathways and problems with coordinating righting reflexes. (White and Dressendorfer 2004 p. 1084)

According to Ferrier et al. (2010 p. 7) people who have MS are decidedly less exertive than the normal population, with only 22% engaging in modest physical activities and 19% in recreational enterprises.

2.2.1 Walking capacity

Up to 85% of people with MS report gait disturbances: their walk is slowed down, the stride length is shortened and the support phase is longer (Kelleher et al. 2010 p. 1242). In a study by Nilsagård et al. (2007 p. 140), it was found that in a sample group of MS clients only 9% rated no limitations in their walking ability. Also, it was documented that persons with moderate MS clearly regard their walking skills as constrained. This is a result of axonal and myelin damage that lead to less motor units being recruited for movement and also slowed down motor firing (White & Dressendorfer 2004 p. 1084). Spasticity is found to have a profound impact on walking capacity. In a study measuring patients' perspective on spasticity and its impact on gait kinematics, it was concluded that those who reported an overall burden of spasticity also had greater gait disturbances (Balantapu et al. 2011 p. 5). Similar findings were made by Kelleher et al. (2010 p. 1242).

Only a few studies have attempted to quantitatively assess gait parameters in MS. Huisinga et al. (2013 p. 308-309) studied the biomechanical gait parameters between MS clients and a healthy control group. They found that joint torques and power during walking was significantly different between the two groups independent of walking speed. During early stance a significant reduction in hip range of motion and ankle power absorption was detected. During preswing the peak plantar flexion was significantly lowered and the torque at toe-off was significantly reduced. The knee extensor torque was significantly lowered during stance.

This could indicate a decreased neuromuscular ability to control the plantar movement during early stance as well as the knee flexors. A reduction in plantar flexion torque leads to less energy being transferred up the kinetic chain to the knee. The reduced neuromuscular control of the hip joint impeded the controlling of the hip with eccentric muscle action in the hip flexors. It also impeded the initiation of concentric muscle action of the hip flexors. (Huisinga et al. 2013 p. 308-309)

In studies of elderly people's gait it was found that compensating techniques were implemented, e.g. increasing power at the hip if the power of the plantar flexion is reduced. It was concluded that this compensating strategy cannot be found in persons with MS. They cannot overcome reduced power at one joint by increasing power at another. Gait problems and the severity of the disease are closely connected. Severe gait problems indicate a severe state of MS. (Huisinga et al. 2013 p. 308)

Changes in gait patterns are of great importance. Dunn (2010 p. 433) states that problems in walking is the primary factor contributing to loss of mobility in MS. Loss of mobility affects many aspects of life: dependency on others increases, the ability to participate in different activities diminishes and the risk of unemployment increases .

2.2.2 Balance

For balance, a person relies on inputs from the visual, somatosensory and vestibular systems. These are frequently impaired in people with MS. They fear falling over and the risk is increased in comparison to the general public (Paltamaa 2012 p. 811, 821). Rautiainen and Tienari (Soinila et al. 2006 p. 388) state that problems with coordination is the most difficult symptom in 5% of all MS patients. Other symptoms related to balance problems are increased sway in quiet stance, response time delay and reduced capacity to move towards their limits of stability (Paltamaa 2012 p. 811). According to Rautiainen and Tienari (Soinila et al. 2006 p. 388) medicine can do little to help with balance problems. They recommend aids and rehabilitation to best cope and find coping strategies for living with balance problems. Paltamaa (2012 p. 820-821) concluded that there is a need to implement in physiotherapy exercises that target different aspects of balance and are specific enough to produce a response. Overall good training levels in resistance and aerobic training have an effect on a person's balance.

2.3 Cognitive functioning in MS

Cognition refers to the integrated functions of the human mind and involves the acquisition, processing and application of information. When a person receives a MS diagnosis he or she will look to their past experiences and coping strategies to best handle their situation and cope with possible physical impairments (Stineman et al. 2007 p. 679, Shevil & Finlayson 2006 p. 780). Loss of cognitive functioning can result in feelings of losing control and confidence. Cognitive impairment can affect memory, concentration, information processing and result in difficulties when performing everyday tasks (Shevil & Finlayson 2006 p. 784). This combined with the need for equilibrium, a balance, makes the MS diagnosis with possibly both physical and cognitive difficulties particularly challenging and calls for great inner coping strategies and outer support.

It is important to have an understanding of the effects of MS on cognitive functioning. MS clients are expected to answer subjective self-reports and knowing how MS itself can affect that person is of value when interpreting the answers.

2.4 The impact of MS on perception and self-efficacy

The general public's perception of the biggest obstacle to not participating in exercise is not having enough time. For people with MS the biggest obstacle is reported to be physical exertion, fatigue. This is interestingly contradicting the fact that exercise intervention has been reported to improve and lower the levels of fatigue (Stroud et al. 2009 p. 2221). The question that presents itself is then that why don't people with MS exercise if they are told it is beneficial to them?

Stroud et al. (2009 p. 2221) claim that "even when the perceived benefits of an activity are high and perceived barriers are low, an individual may not engage in an activity if perceived self-efficacy is low". Here, self-efficacy is defined as people's beliefs about their capabilities to perform a given task. In their study, an exercising group and a non-exercising group both reported comparable lists of benefits and barriers to exercising. A major finding was that self-efficacy was reported higher in the group that did exercise. Dunn (2010 p. 435) states that self-efficacy may play a role in the strong inverse

relationship between physical activity and MS symptoms, especially motor symptoms. Contrarily, Kosma et al. (2002 p. 7) studied clients with physical disabilities and found the link between predicting physical activity and self-efficacy only at baseline and not after one year of rehabilitation. In conclusion, while self-efficacy plays a role in the beginning to help initiate exercise, its influence diminishes over time. In the long term, perceived benefits from the activity and also deeper behavioral changes in the person towards physical activity were important factors for keeping physically active.

2.5 Subjective and objective outcome measures

There is unanimity among researchers that a person's beliefs play an important role as to how that person copes and deals with his or her MS diagnosis (Kayes et al. 2011 p. 1044). However, there is no wide consensus among researchers of how a person's own perception is in line with what can be objectively measured. According to both Nilsagård et al. (2007 p. 140) and Goverover et al. (2005 p. 2306), objective and subjective measures provide valuable results to the evaluation of the rehabilitation. Ferrier et al. (2010 p. 10.) found that a person who believed they could exercise, overcome barriers when exercising and thought that exercise would have a positive effect on their health, were more likely to be active.

Stuifbergen et al. (2014 p. 5) studied fine and gross motor function in persons with MS using self-reports and performance measures. It was concluded that there is primary support for a correlation between these. Then again Goverover et al. (2005 p. 2306) studied ADL (Activities in Daily Living) in persons with MS using subjective and objective measurements. It was found that there is no correlation between the results. Further research on the link between measurement methods in MS patients is necessary.

According to Stuifbergen et al. (2014 p. 2), in the beginning of treatment subjective self-reports can offer prognostic assessment of a person's physical abilities. But to solely rely on self-reports is also not an option as it has been shown that e.g. depression can affect how a person replies and can influence answers concerning physical abilities (Goverover et al. 2005 p. 2304). Depression is a common symptom in MS; up to 50% suffer from it, partly because of the neuroendocrine changes in the brain (White and Dressendorfer 2004 p. 1084).

A diagnostic process, where co-operation between the neurologist and the patient exists using subjective and objective measurements, could prove more beneficial than relying solely only on one of these methods (Pugliatti et al. 2008 p.161).

3 REHABILITATION PRAXIS IN FINLAND

The one year timeline in which the testing had been set up in this study is closely connected to how the Finnish rehabilitation system works and therefore for the reader to understand the Finnish rehabilitation system in general and in that context is important. The Finnish law (KKRL 566/2005 10 §) insists on making an individual rehabilitation plan that is valid from one year to three years at a time. (Paltamaa et al. 2011 p. 35 – 38)

In Finland national health care follows Current Care Guidelines which are evidence based practice guidelines how to diagnose and treat patients. According to these guidelines every MS patient has the right to be evaluated for his or her need for rehabilitation. Especially important is the evaluation of maintaining physical functioning at such a level that working ability maintained. (Käypähoito, www, 15.2.2015) This study is also contributing to this process, understanding the evaluation process and using the correct tests is essential.

Medical rehabilitation need must be assessed and provided according to the need by the patient's community. One tool for the assessment is the EDSS scale (Expanded Disability Status Scale). If the patient is severely disabled and under 65 years old, the medical rehabilitation must be provided by Kela, which is an independent social security institution. (Käypähoito, www, 15.2.2015)

According to Finnish law (KKRL 566/2005 10 §) rehabilitation needs to be conducted with good rehabilitation practices and by a rehabilitation specialist. Good rehabilitation is further explained as customer and family oriented and it is always anchored in the daily living of the client. The rehabilitation plan is conducted with a multidisciplinary team in co-operation with the client. Working in multidisciplinary teams is beneficial; a team can consist of e.g. a neurologist, a physiotherapist and a social worker. The rehabilitation plan must consist of a description of the client's ability to function and measurements used to obtain this information. (Paltamaa et al. 2011 p. 35 – 38)

4 AIM OF THIS STUDY

Evaluating clients with the appropriate measurements is important for rehabilitation to be successful. The Finnish rehabilitation system is often built up in a one year timeline. Therefore this study delves into the different measurements used and the rehabilitation process in a one year timeline. Findings of this study may contribute new knowledge and can add to the rehabilitation evaluation system in Outpatient Rehabilitation Center Aksoni.

- I What relations can be found when evaluating results for persons with MS with subjective self-report measures and objective performance based walking tests?**

- II What relations can be found between set goals, volume of rehabilitation, client's impression of change and the objectively measured walking capacity?**

5 METHOD

This study uses a case study approach. According to Cohen et al. (2007 p. 253-254), case studies can penetrate situations in ways that are not susceptible to numerical analysis alone. Case study methodology allows investigating complex dynamic and unfolding interactions between persons and events.

Historically the case study method has been critiqued, mainly by devoted quantitative researchers. The accusations involve lack of trust in validity and reliability of the method. Other researchers argue the contrary, that case study is suited to both quantitative and qualitative research and is a completely well-founded research method with many unique qualities. (Cronin 2014 p. 20, Eisenhardt 1989 p. 534, Yin 2006 p. 13)

Case study is an empirical study where the study is based on observing and measuring. It is a good method when the relationship between cause and effect is complicated and intertwined. (Laitinen 1998 p. 19, Yin 2006 p. 24-25) Case study often researches a chain of events and not a single statistical unit (Laine 2007 p. 9, 105-106). This study observes MS clients in a one year timeframe according to Finnish rehabilitation standards (Kela kuntoutustyöryhmä, 2014, www). Used measurements are the MS client's subjective self-report and the objective performance based walking tests.

Case studies are situated in real life context with the investigator often integrally involved in the cases (Yin 2006 p. 25, Bowling 1998 p. 359). Case data is gathered systematically using different forms of data gathering. A case is a single unit in a study; it can be a person or a setting such as a clinic (Bowling 1998 p. 359). In this study the case to be studied is the Outpatient Rehabilitation Center Aksoni and the study population selected from within. The study was deeply integrated with the MS clients' own rehabilitation process. This study recorded subjective views through self-reports, walking ability through objective performance based walking tests and volume of rehabilitation (group rehabilitation, individual rehabilitation and autonomous training). The research did not wish to interfere or intervene in the rehabilitation process.

Case study is most useful in the gap between using purely a quantitative statistical approach and the need to study a single case in more depth. A quantitative approach

often entails large quantities of data with researchers trying to distance themselves from the study objects. Case study allows for a more in depth study of a particular case and the processes within. (Laitinen 1998 p. 17, Laine 2007 p. 51-54)

To answer these questions a comparative case study research method is used. Measures of central tendencies are used to show data from the subjective and objective tests. Central tendencies, also more commonly known as average scores were counted using the Arithmetic mean. An average is used to condense information so that information is easier to compare. (Caswell 2001 p. 84)

The Arithmetic mean \bar{x} is defined as

$$\bar{x} = \frac{1}{n} \sum_{i=1}^n x_i$$

where n is the number of terms (e.g. the number of items or numbers being averaged), and x_i is the value of each individual item in the list of numbers being averaged. (Caswell 2001 p. 85, 90)

Also, statistic calculations were made to verify the results from the comparative analysis, for research question I, by looking for correlations between the measurements used at Baseline, Test 1 and Test 2.

The statistic calculations include the standard deviation, which provides a measure of spread of the mean (Hinton 2008 p. 16). According to Caswell (2001 p. 111) the standard deviation is the most important measure of spread when calculating advanced statistics. The Standard Deviation SD is defined as

$$SD = \sqrt{\frac{\sum(x - \bar{x})^2}{n}}$$

where x is each value in the data, \bar{x} is the Arithmetic mean and n is the number of values in the data set (Eggeby & Söderberg 2000 p.82).

For calculating the correlations between the selected measures the Pearson correlation was used. The correlation tells us if there is a relationship between two sets of data. If

there is a positive correlation then a change in one can predict a change in the other.
(Hinton 2008 p. 262)

The Pearson correlation r is defined as

$$r = \frac{\sum_{i=1}^n (x_{1,n} - \bar{x}_1)(x_{2,n} - \bar{x}_2)}{\sqrt{\sum_{i=1}^n (x_{1,n} - \bar{x}_1)^2 \sum_{i=1}^n (x_{2,n} - \bar{x}_2)^2}}$$

where x_1 and x_2 are data sets 1 and 2, respectively.

The case to be studied is presented in Table 2. It illustrates the Aksoni case study and the case study methodology in general.

Table 2. Case study methodology and Aksoni case study (Laine 2007 p. 12, 56).

CASE STUDY CHARACTERISTICS	AKSONI CASE STUDY
The target to be studied is a small population	Outpatient Rehabilitation Center Aksoni, 21 clients
A large amount of data is gathered	Both subjective and objective measurements were used in a one year timeframe with three sets of measurements taken.
The goal is to provide a description of a phenomenon (Eisenhardt 1989 p.535).	The aim in this thesis is to see what relations can be found when evaluating MS clients with subjective self-report measures and objective performance based walking tests and between set goals, volume of rehabilitation, client's impression of change and the objectively measured walking capacity.
The researcher is often integrally involved and is left with the responsibility to present the case as it is. The final conclusions are left up to the reader.	Author is integrally involved and will try to deliver answers and recordings of the results in such a way that the reader has the chance to interpret the results.

5.1 Study timeline

The study started in Aksoni in fall 2011 with baseline testing. The next measurements were conducted 2-3 months later and the third and last measurements 9-12 months from the baseline measurements. The study timeline is presented in Table 3.

Table 3. Study timeline and used abbreviations.

Baseline (BT)	Test 1 (T1)	Test 2 (T2)
0	2 – 3 months after baseline	9 – 12 months after baseline

5.2 Subjects, design and ethical approval

Altogether 23 clients from Aksoni participated. Two clients dropped out due to leg sprain and missing the last test opportunity, respectively. These two clients' results were excluded entirely from the study. Data of a third client concerning volume of rehabilitation and context was not available from the last test session leading to exclusion from the secondary research question.

9 of the participating clients have relapsing-remitting MS, 10 clients have secondary progressive MS and 2 have primary progressive MS. The participants' ages ranged from 37 to 63 years (average 52.7 years). The shortest amount of time since MS diagnosis was 6 years and the longest was 41 years (average 15.5 years). 8 of the clients are men and 13 are women.

The study population of this thesis was recruited from the clientele of Outpatient Aksoni. The study population consisted of ambulatory persons with MS and were included or excluded by the following criteria:

- *Inclusion criteria:* a definitive diagnosis of MS according to the McDonald criteria and Expanded Disability Status Scale (EDSS) score ≤ 6.5 .
- *Exclusion criteria:* other conditions (e.g. orthopedic, cardiorespiratory) interfering with walking.

The study population and the inclusion and exclusion criteria were defined by the multicenter study. The same study population with the same inclusion and exclusion criteria took part in this thesis.

All provided written informed consent and the multicenter study was approved by the Ethical Committee of Hasselt University, Belgium. This study was approved in Proper Finland by the local health care districts ethical committee.

The descriptive outcome measures used

- full name
- patient number
- gender
- age
- height (cm)
- weight (kg)
- years since diagnosis of MS
- *type of MS*: relapsing-remitting MS / secondary progressive MS / primary progressive MS
- EDSS (range 0-6.5)

Primary outcome measures at baseline

- *Short walk test*: Timed 25-Foot walk test
- *Long walk test*: 2 minute walk test and 6 minute walk test.
- MS Walking Scale (MSWS-12)
- Visual Analogue Scale (VAS)

Secondary and third outcome measures (T1 and T2)

A questionnaire completed by the participant enquiring the participant's impression of change. The same walk tests and questionnaires as in the baseline were tested and given to the participants in the same order as during the baseline. Just before the post-assessments, the treating physiotherapist also filled in a questionnaire about the context of the rehabilitation, primary goal and duration of the physical rehabilitation.

5.3 Tests used

MS Walking Scale (MSWS-12) is a questionnaire with standardized questions about the limitations to the clients walking, climbing stairs and running. Additionally, the need for support when moving during the past two weeks is recorded with pre-coded response choices. MSWS-12 was created in 2003 for MS client's self-examination and has been widely used in research (www, TOIMIA 2015).

An example question is presented in Table 4. The scores range from 12 to 60. The entire MSWS-12 questionnaire is presented in *Appendix 3*.

Table 4. An example question and response choices from the MSWS-12 questionnaire.

Question: How much has MS limited your walk?				
Not at all	A little	Moderately	Quite a bit	Extremely
1	2	3	4	5

Visual Analogue Scale (VAS) is a tool used here for questioning the client about how confident they have felt about their balance during the past week. The given answers on the scale are interpreted to numerical data. The scale is 0 – 10 cm with 0 being “not confident at all” and 10 being “very confident”. VAS walking is used to question the client about how confident they have felt about their walking capacity during the past week. See *Appendix 3 (2/2)* for the original VAS balance and walking questionnaire.

The two minute and six minute walk tests are by definition long walk tests. The testing order was determined randomly and then kept the same for all test occasions. Between the long walk tests a rest period of 15 minutes was held. In both walk tests participants walked back and forth along a 30 meter hallway, turning around cones at each end. They were allowed to use their habitual assistive device at each testing session. See *Appendix 2*.

The timed 25-foot (7.62 m) walk tests are defined as short walk tests. Clients were instructed to walk the timed 25-foot walk test first at their own usual and comfortable speed. After a one minute rest they completed the same test as fast as possible. For further information, see *Appendix 1*.

Impression of change (IOC) was asked with seven pre-coded response choices (ranging from 1 “very much worse” to 7 “very much improved, see *Appendix 4* by asking: *Compared to before the intervention period/before starting rehabilitation at this center, how would you rate your walking now?*

5.4 Data analyzing

Data analyzing can be done in many different ways in a case study and is often the most difficult part. This study has used a cross-case pattern analyzing process by Eisenhardt (1989 p. 540) which has also been recommended by Cronin (2014 p. 22). The analyzing process is started by selecting categories, cases or dimensions by the researcher and by looking for group similarities and intergroup differences (Cronin 2014 p. 22). This is a good tactic to use as it diminishes premature and false conclusions as the researcher is forced to go beyond the first impression of the data at hand (Eisenhardt 1989 p. 540, 541).

According to Eisenhardt (1989 p. 541,542), by using these tactics “tentative themes, concepts and possibly even relationships between variables begin to emerge”. However, the researcher must prepare to also reconsider or even invalidate, prove false a relation if it so appears. The process is very similar to traditional hypothesis research. The difference is that the examination is done for each case, or in this study for the selected groups. Every group is treated as its own experiment and conclusions are drawn every time. This repetitiveness enhances the validity of the relations found. Eisenhardt (1989 p. 542) also states that “cases which disconfirm the relationships often can provide an opportunity to refine and extend the theory”. (Eisenhardt 1989 p. 541-542)

For research question I analysis the clients were divided into four groups based on their EDSS score (Table 5).

Table 5. EDSS definitions and group classification. (Kurtzke 1983 p.1451). For the full range of the Expanded Disability Status Scale, see Appendix 6.

Group EDSS 4.0-4.5 (n = 3)	4.0 - Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1), or combination of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 500 meters.
	4.5 - Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterized by relatively severe disability usually consisting of one FS grade 4 (others or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 300 meters.
Group EDSS 5.0-5.5 (n = 3)	5.0 - Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (e.g., to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combinations of lesser grades usually exceeding specifications for step 4.0).
	5.5 - Ambulatory without aid for about 100 meters; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0).
Group EDSS 6.0 (n = 12)	Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).
Group EDSS 6.5 (n = 3)	Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).

For research question II the clients were divided for analyzing into four groups based on their primary goal for rehabilitation. The pre-given choices were (for details, see *Appendix 5 2/3*):

- Improving balance at Test 1 n 3 at Test 2 n 1.
- Improving walking capacity at Test 1 n 3 at Test 2 n 6.
- Maintenance of balance and walking at Test 1 n 13 at Test 2 n 12.
- Other, not related to balance and walking at Test 1 n 1 at Test 2 n 1.

6 RESULTS

In the following chapters the main results are presented. Results for research questions I and II are displayed in Chapters 6.1 and 6.2, respectively.

6.1 Relations found when evaluating MS clients' with subjective self-report measures and objective performance based walking tests.

To answer the primary research question the results from the tests are presented in Figures 1-7. Each figure show every clients test results individually. The change in test results are also shown individually. The EDSS score is also shown individually. After every Figure a Table is presented with the group specific test results using calculated averages for the groups and also showing the changes between the different tests in percentage. This data has then been analyzed as described in *Chapter 5.4*.

6.1.1 MS Walking Scale (MSWS-12) - Subjective

The average scores presented in Figure 1 and Table 6 show that the clients, in average, rate themselves having more difficulties at the first testing than at Baseline. By Test 2 they rate their skills better than at Test 1 but worse than at the Baseline. In general all the clients have given themselves high marks in this test, answering most often with “quite a bit” and “extremely”. Even in the lower EDSS range high marks can be observed.

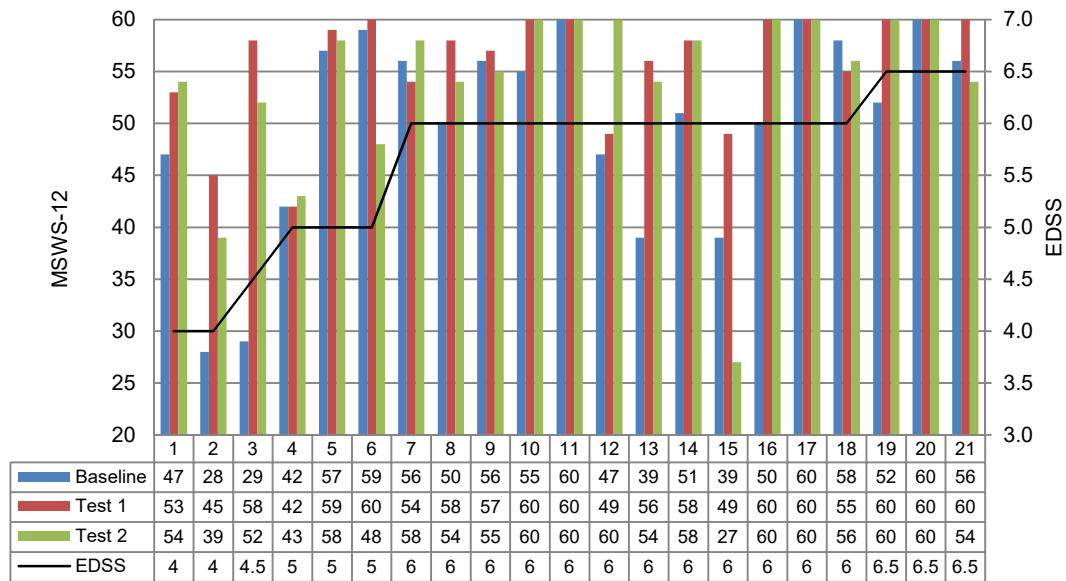


Figure 1. Individual MSWS-12 results from three test sessions.

Table 6. Group specific MSWS-12 results from three test sessions.

Group EDSS	MSWS-12 [12-60]			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	34.7	52.0	48.3	+50.0%	+39.4%
5.0-5.5	52.7	53.7	49.7	+1.9%	-5.7%
6.0	51.8	56.3	55.2	+8.9%	+6.6%
6.5	56.0	60.0	58.0	+7.1%	+3.6%
all	50.0	55.9	53.8	+11.6%	+7.5%

Group EDSS 4.0-4.5: This group reports a 50.0% higher difficulty at Test 1 compared to Baseline. At Test 2 the results show slight improvement.

Group EDSS 5.0-5.5: Scores are overall more stable throughout the tests in this group.

Group EDSS 6.0: At Test 1 8.9% higher scores are given compared to Baseline. At Test 2 the average score decreases compared to Test 1 but is still 6.6% higher than at Baseline.

Group EDSS 6.5: This group follows the same trend as above. Clients report 7.1% and 3.6% more difficulties at Test 1 and Test 2, respectively.

All groups, as well as the average of all results, show similar trends. Firstly, experienced difficulty increases between Baseline and Test 1. Then between Test 1 and Test 2, the feeling of difficulty decreases.

6.1.2 Visual Analogue Scale, Balance - Subjective

VAS balance results are presented in Figure 2 and Table 7. The VAS-balance average score tells us that clients rate themselves as having less confidence in balance at Test 1 in comparison to the Baseline. At Test 2, confidence increases and they feel themselves having almost exactly the same amount of confidence than at Baseline. The trend seen here was also obvious in the MSWS-12 measurement. No clear trends between groups can be observed.

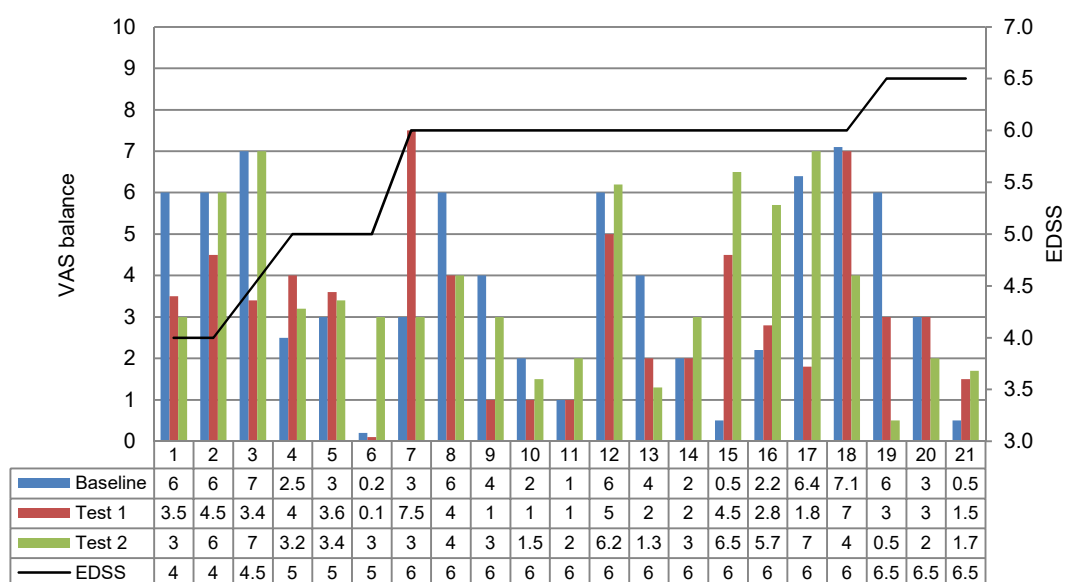


Figure 2. Individual VAS balance results from three test sessions.

Table 7. Group specific VAS walking results from three test sessions.

EDSS	VAS walking [0-10]			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	6.3	3.8	5.3	-40.0%	-15.8%
5.0-5.5	1.9	2.6	3.2	+35.1%	+68.4%
6.0	3.7	3.3	3.9	-10.4%	+6.8%
6.5	3.2	2.5	1.4	-21.1%	-55.8%
all	3.7	3.2	3.7	-15.6%	+1.8%

Group EDSS 4.0-4.5: Confidence in balance dropped at Test 1 compared to Baseline to increase again at Test 2.

Group EDSS 5.0-5.5: Interestingly confidence starts at a very low point, but increases steadily through Test 1 and Test 2.

Group EDSS 6.0: Confidence in balance dropped at Test 1 compared to baseline to increase again above Baseline at Test 2. Scores are stable throughout the tests.

Group EDSS 6.5: Confidence in balance drops both at Test 1 and Test 2.

6.1.3 Visual Analogue Scale, Walking - Subjective

A summary of VAS walking results is presented in Figure 3 and Table 8. On average the clients have less confidence in their walking skills at Test 1 in comparison to Baseline. The results of Test 2 show a slight improvement compared to Test 1. This trend is equivalent to observations in MSWS-12 and VAS-balance scores.

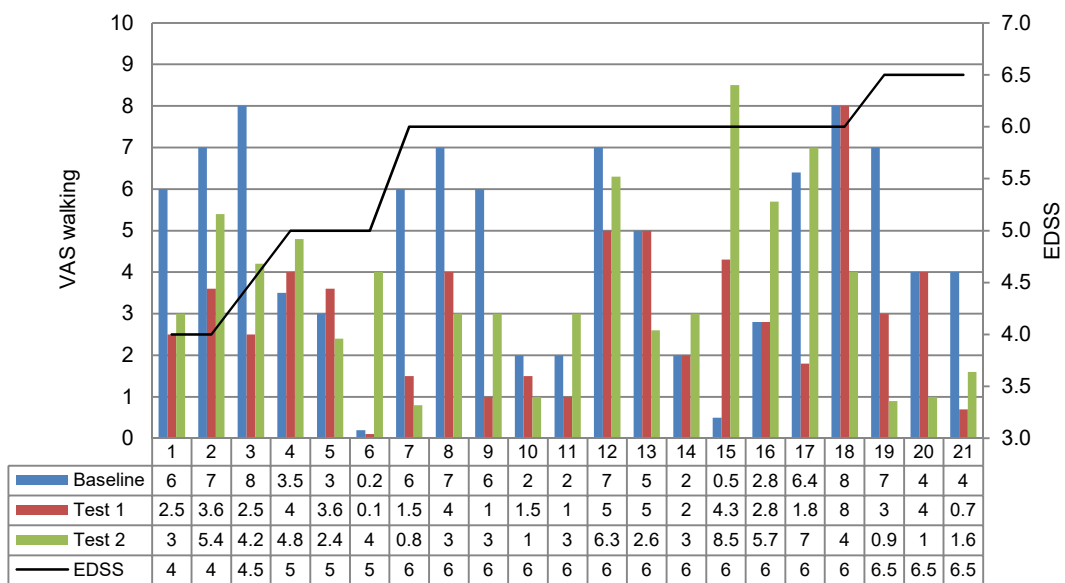


Figure 3. Individual VAS walking results from three test sessions.

Table 8. Group specific VAS walking results from three test sessions.

EDSS	VAS walking [0-10]			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	7.0	2.9	4.2	-59.0%	-40.0%
5.0-5.5	2.2	2.6	3.7	+14.9%	+67.2%
6.0	4.6	3.2	4.0	-30.7%	-12.4%
6.5	4.6	2.9	4.0	-37.7%	-13.5%
all	4.6	2.9	3.6	-36.4%	-22.8%

Group EDSS 4.0-4.5: Confidence in walking starts strong as it did in VAS-balance. A substantial decrease in confidence occurs at Test 1 compared to Baseline to increase again at Test 2.

Group EDSS 5.0-5.5: Growing confidence in walking can be observed throughout the tests as it did in VAS-balance.

Group EDSS 6.0: Confidence in walking dropped at Test 1 compared to Baseline to increase again above Baseline at Test 2. The same trend occurred in MSWS-12 and VAS-balance tests.

Group EDSS 6.5: Confidence in balance dropped at Test 1 compared to baseline to increase again at Test 2.

6.1.4 Two Minute Walk Test - Objective

Figure 4 and Table 9 present the results of 2 min walk tests. Both long walk test measured distance. For the analysis, the results were converted to meters per minute. This will improve and facilitate comparison between all walk tests. See *Appendix 1 (2/3)* for further information

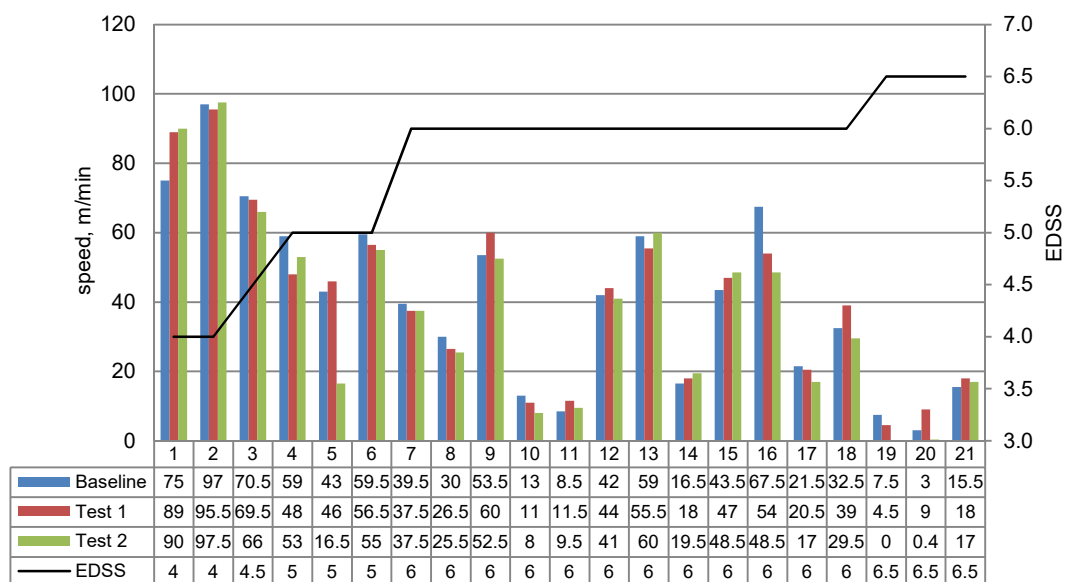


Figure 4. Individual 2 min walk test results from three test sessions.

Table 9. Group specific 2 min walk test results from three test sessions.

EDSS	2 min walk test, m/min			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	80.8	84.7	84.5	+4.7%	+4.5%
5.0-5.5	53.8	50.2	41.5	-6.8%	-22.9%
6.0	35.6	35.4	33.1	-0.6%	-7.0%
6.5	8.7	10.5	5.8	+21.2%	-33.1%
all	40.8	41.0	37.7	+0.4 %	-7.5 %

Group EDSS 4.0-4.5: An improvement in test results can be observed in both Test 1 and Test 2 compared to Baseline.

Group EDSS 5.0-5.5: A steady deterioration in walking compared to Baseline can be seen throughout the tests.

Group EDSS 6.0: A small deterioration in walking results compared to Baseline can be observed at Test 1. A more substantial deterioration in walking results is seen in Test 2 compared to Baseline.

Group EDSS 6.5: An improvement in walking results is seen at Test 1. The results deteriorate by Test 2.

Interestingly, clients with the smallest and largest EDSS score improved their walking results by Test 1. Only the group with the smallest EDSS score improved also at Test 2. Another interesting observation is that walking distance correlates well with the EDSS score in all tests.

6.1.5 Six Minute Walk Test - Objective

Figure 5 and Table 10 present the results from the six min walk tests, see *Appendix 2* for further information on the six minute walk test.

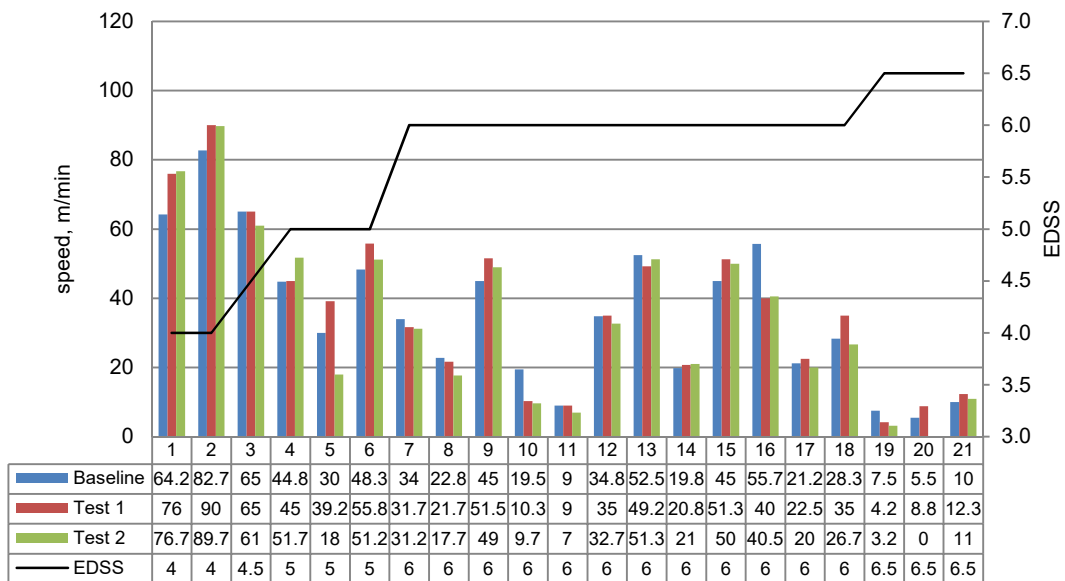


Figure 5. Individual 6 min walk test results from three test sessions.

Table 10. Group specific 6 min walk test results from three test sessions.

EDSS	6 min walk test, m/min			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	70.6	77.0	75.8	+9.0%	+7.3%
5.0-5.5	41.0	46.7	40.3	+13.7%	-1.8%
6.0	32.3	31.5	29.7	-2.5%	-7.9%
6.5	7.7	8.4	4.7	+10.0%	-38.3%
all	35.5	36.9	34.3	+3.8 %	-3.5 %

Group EDSS 4.0-4.5: An improvement in walking results can be seen in both Test 1 and Test 2 compared to Baseline. Interestingly the improvements follow the same trend as in the 2 minute walk test showing longest walking distances at Test 1.

Group EDSS 5.0-5.5: An improvement can be observed at Test 1. Test results deteriorate at Test 2.

Group EDSS 6.0: Deterioration in walking results compared to Baseline can be seen at both Test 1 and 2.

Group EDSS 6.5: An improvement in walking results is recognized at Test 1. The results deteriorate by Test 2. This group shows the largest fluctuation between walking test results in both long walk tests.

Three different groups improved their walking results by Test 1. Only clients who scored 4.0-4.5 in EDSS improved also at Test 2 – as was the case in the 2 minute walk test. Also in the 6 minute walk test, walking distance correlates well with EDSS at all tests.

6.1.6 Timed 25-Foot Walk Test, Usual Speed - Objective

In Figure 6 and Table 11 the converted results are presented and compared for the Timed 25-Foot walk test. For further information on the test please see *Appendix 1*.

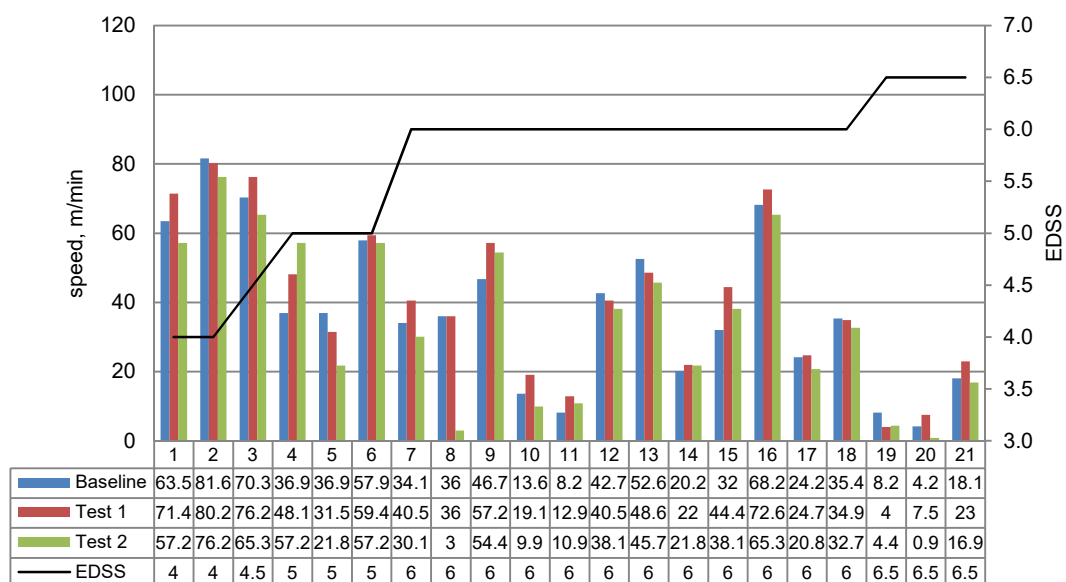


Figure 6. Individual 25 ft walk test results at usual speed from three test sessions.

Table 11. Group specific 25 ft walk test results at usual speed from three test sessions.

EDSS	25 ft usual speed, m/min			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	71.8	75.9	66.2	+5.8%	-7.8%
5.0-5.5	43.9	46.3	45.4	+5.5%	+3.4%
6.0	34.5	37.8	30.9	+9.5%	-10.4%
6.5	10.2	11.5	7.4	+13.1%	-27.2%
all	37.7	40.7	34.7	+8.0 %	-8.0 %

Group EDSS 4.0-4.5: At Test 1 an improvement in usual speed is observed. At Test 2 the usual speed has declined compared to Baseline.

Group EDSS 5.0-5.5: Small improvements can be seen at both tests.

Group EDSS 6.0: At Test 1 an improvement in usual speed is observed. At Test 2 the results have declined compared to Baseline.

Group EDSS 6.5: At Test 1 usual walking speed has slightly improved. At Test 2 the usual speed has declined compared to Baseline.

The results indicate that on average the comfortable walking speed initially increases. However, by Test 2 a negative development is noted.

The author has decided to exclude the usual speed results from the objective walking test results in both research questions. Usual walking speed reflects a client’s own perception and not solely the objectively measured results.

6.1.7 Timed 25-Foot Walk Test, Fast Speed – Objective

The description of timed 25-foot walk tests at fastest possible speed (Figure 7 and Table 12) is given in Chapter 5.3 and *Appendix 1*. On average clients walked steadily slower at each test.

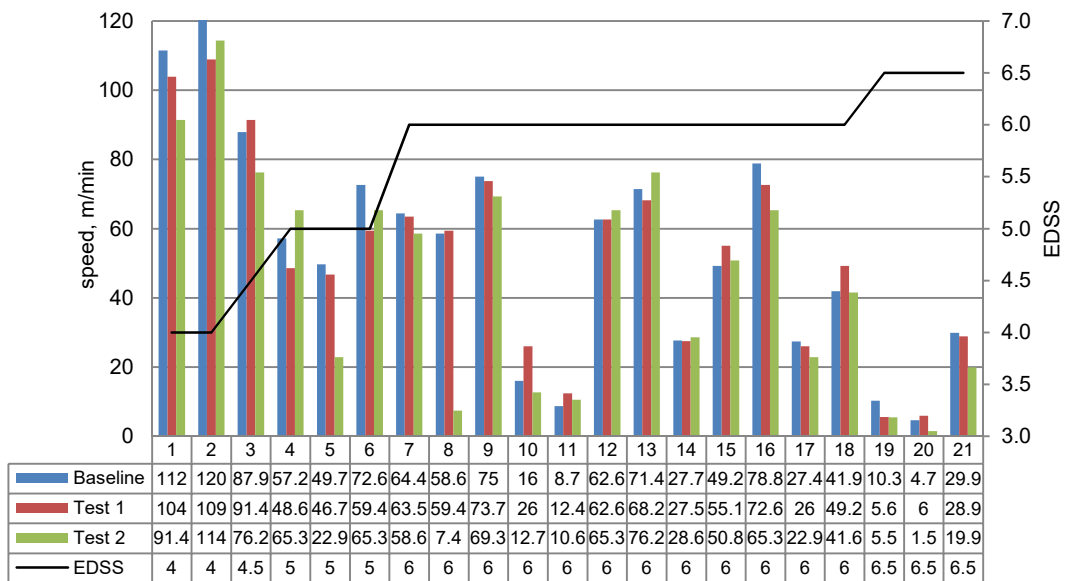


Figure 7. Individual 25 foot walk test results at fast speed from three test sessions.

Table 12. Group specific 25 foot walk test results at fast speed from three test sessions.

EDSS	25 ft fast, m/min			Change [%]	
	Baseline	Test 1	Test 2	BL-T1	BL-T2
4.0-4.5	106.6	101.4	94.0	-4.8%	-11.8%
5.0-5.5	59.8	51.6	51.2	-13.8%	-14.5%
6.0	48.5	49.7	42.4	+2.5%	-12.4%
6.5	15.0	13.5	9.0	-9.8%	-40.1%
all	53.6	52.2	46.3	-2.7 %	-13.7 %

Group EDSS 4.0-4.5: A steady decline can be observed as the clients walk faster at Baseline compared to both Tests.

Group EDSS 5-5.5: On average results decline after Baseline.

Group EDSS 6.0: Walking results improve at Test 1 compared to Baseline. Results deteriorate at Test 2 as clients walk slower than at Baseline.

Group EDSS 6.5: A deterioration can be seen at both tests, especially at Test 2.

6.1.8 Summary for the EDSS groups

Below are presented the summary for all the results for the different EDSS groups (Tables 13-16).

Table 13. A summary of subjective and objective measurements for clients with an EDSS score 4.0-4.5.

	Baseline	Test 1	Test 2	Change, %	
				BL-T1	BL-T2
MSWS-12	34.7	52.0	48.3	+50.0%	+39.4%
VAS-balance	6.3	3.8	5.3	-40.0%	-15.8%
VAS-walking	7.0	2.9	4.2	-59.0%	-40.0%
25-foot, fast, m/min	106.6	101.4	94.0	-4.8%	-11.8%
2 min walk test, m/min	80.8	84.7	84.5	+4.7%	+4.5%
6 min walk test, m/min	70.6	77.0	75.8	+9.0%	+7.3%

For clients with a low EDSS score long walk test results improved at both tests compared to Baseline (Table 13). The short walk test result deteriorated at both tests. Interestingly, all subjective measures show a decline in results: confidence in walking and balance declined and feelings of difficulty in walking based on MSWS-12 increased. In Test 1, deterioration in the short walk test and declined subjective results are contradictory to improved long walk test results. Another observation is that the subjective measures show a negative development at Test 1 and a slight improvement at Test 2. A clear relation between all subjective measures can be observed as the results follow each other. No clear relation is detected between the subjective and objective measurements.

Table 14. A summary of subjective and objective measurements for clients with an EDSS score 5.0-5.5.

	Baseline	Test 1	Test 2	Change, %	
				BL-T1	BL-T2
MSWS-12	52.7	53.7	49.7	+1.9%	-5.7%
VAS-balance	1.9	2.6	3.2	+35.1%	+68.4%
VAS-walking	2.2	2.6	3.7	+14.9%	+67.2%
25-foot, fast, m/min	59.8	51.6	51.2	-13.8%	-14.5%
2 min walk test, m/min	53.8	50.2	41.5	-6.8%	-22.9%
6 min walk test, m/min	41.0	46.7	40.3	+13.7%	-1.8%

In Table 14, a summary of results for clients in Group EDSS 5.0-5.5 is shown. Walking test results improved only in the six minute walk test at Test 1. All other walking test results declined. Interestingly, subjective measures show an increase in confidence at both VAS tests. Only small changes in MSWS-12 scores can be seen. This group feels more confident which is in contradiction to the objective walking test results. Between Test 1 and Test 2, subjective measures show improvement while objective measures show declined walking ability. No clear relation is detected between the subjective and objective measurements.

Table 15. A summary of subjective and objective measurements for clients with an EDSS score 6.0.

	Baseline	Test 1	Test 2	Change, %	
				BL-T1	BL-T2
MSWS-12	51.8	56.3	55.2	+8.9%	+6.6%
VAS-balance	3.7	3.3	3.9	-10.4%	+6.8%
VAS-walking	4.6	3.2	4.0	-30.7%	-12.4%
25-foot, fast, m/min	48.5	49.7	42.4	+2.5%	-12.4%
2 min walk test, m/min	35.6	35.4	33.1	-0.6%	-7.0%
6 min walk test, m/min	32.3	31.5	29.7	-2.5%	-7.9%

As shown in Table 15, walking test results deteriorate slightly over time for clients with EDSS score 6.0. Confidence measured with VAS and feelings of difficulty in walking measured with MSWS-12 were nearly constant. At Test 1, subjective views and the results from the walking tests show similar development the same trend cannot be seen at Test 2 where subjective views improve but walking test results decline. A clear relation between all subjective measures can be observed as the results follow each other.

Table 16. A summary of subjective and objective measurements for clients with an EDSS score 6.5.

	Baseline	Test 1	Test 2	Change, %	
				BL-T1	BL-T2
MSWS-12	56.0	60.0	58.0	+7.1%	+3.6%
VAS-balance	3.2	2.5	1.4	-21.1%	-55.8%
VAS-walking	4.6	2.9	4.0	-37.7%	-13.5%
25-foot, fast, m/min	15.0	13.5	9.0	-9.8%	-40.1%
2 min walk test, m/min	8.7	10.5	5.8	+21.2%	-33.1%
6 min walk test, m/min	7.7	8.4	4.7	+10.0%	-38.3%

Results from the 25-foot walk test deteriorate over time for Group EDSS 6.5 (Table 16). Long walk test results improve at Test 1 compared to Baseline but decline rapidly in Test 2. MSWS-12 scores are near the upper limit. According to VAS results, balance deteriorates more than walking. No clear relation can be seen at Test 1: subjective measures show decline as well as the 25-foot walk test. However, all long walk test

results improve at the same time. Consensus is though found between the different measurements from Baseline to Test 2 as they all indicate negative development.

6.1.9 Summary for the entire study population

In Table 17 the averages for the entire study populations are shown.

Table 17. A summary of subjective and objective measurements for all clients.

	Baseline	Test 1	Test 2	Change, %	
				BL-T1	BL-T2
MSWS-12	50	55.9	53.8	+11.6	+7.5
VAS-balance	3.7	3.2	3.7	-15.6	-1.8
VAS-walking	4.6	2.9	3.6	-36.4	-22.8
25-foot, fast, m/min	53.6	52.2	46.3	-2.7	-13.7
2 min walk test, m/min	40.8	41.0	37.7	+0.4	-7.5
6min walk test, m/min	35.5	36.9	34.3	+3.8	-3.5

At Test 1 all long walk tests improve compared to Baseline. In contradiction, clients feel they have less confidence in walking and balance at Test 1. They also feel themselves having more difficulty in walking. The short walk test results deteriorate over time. However, clients' confidence grows towards Test 2 and feelings of difficulty diminish, but the walk test results deteriorate even further showing no clear relation.

A relation was detected between the given EDSS and the objective walk test results. An interesting trend was also detected between the different subjective tests as they all declined in Test 1 and all improved in Test 2. A relation between the different subjective self-reports was seen.

6.1.10 Statistical significance

Table 18. Pearson correlation coefficient and two-tailed P-value for Baseline, Test 1 and Test 2. If the absolute value of the Pearson correlation is larger than 0.549, then the correlation is statistically significant (P-value 0.01).

Baseline	6min walk test	2 min walk test	25-foot, fast	MSWS-12	VAS-balance	VAS-walking	Pearson P-value (2-t)
6min walk test 35.5 ± 21.3		0.984 0.000	0.945 0.000	-0.741 0.000	0.241 0.292	0.167 0.469	
2 min walk test 40.8 ± 25.7	0.984 0.000		0.963 0.000	-0.687 0.001	0.237 0.301	0.185 0.421	
25-foot, fast 53.6 ± 32.2	0.945 0.000	0.963 0.000		-0.634 0.002	0.317 0.161	0.298 0.190	
MSWS-12 50.0 ± 9.7	-0.741 0.000	-0.687 0.001	-0.634 0.002		-0.302 0.184	-0.256 0.263	
VAS-balance 3.7 ± 2.3	0.241 0.292	0.237 0.301	0.317 0.161	-0.302 0.184		0.921 0.000	
VAS-walking 4.6 ± 2.4	0.167 0.469	0.185 0.421	0.298 0.190	-0.256 0.263	0.921 0.000		

Test 1	6min walk test	2 min walk test	25-foot, fast	MSWS-12	VAS-balance	VAS-walking	Pearson P-value (2-t)
6min walk test 36.9 ± 23.3		0.985 0.000	0.921 0.000	-0.561 0.008	0.195 0.396	0.121 0.602	
2 min walk test 41.0 ± 25.5	0.985 0.000		0.954 0.000	-0.529 0.014	0.210 0.361	0.123 0.597	
25-foot, fast 52.2 ± 29.5	0.921 0.000	0.954 0.000		-0.478 0.028	0.293 0.198	0.118 0.610	
MSWS-12 55.9 ± 5.4	-0.561 0.008	-0.529 0.014	-0.478 0.028		-0.523 0.015	-0.415 0.062	
VAS-balance 3.2 ± 1.9	0.195 0.396	0.210 0.361	0.293 0.198	-0.523 0.015		0.648 0.002	
VAS-walking 2.9 ± 1.8	0.121 0.602	0.123 0.597	0.118 0.610	-0.415 0.062	0.648 0.002		

Test 2	6min walk test	2 min walk test	25-foot, fast	MSWS-12	VAS-balance	VAS-walking	Pearson P-value (2-t)
6min walk test 34.3 ± 24.5		0.990 0.000	0.958 0.000	-0.605 0.004	0.446 0.043	0.456 0.038	
2 min walk test 37.7 ± 27.3	0.990 0.000		0.964 0.000	-0.546 0.01005	0.419 0.059	0.412 0.063	
25-foot, fast 46.3 ± 31.9	0.958 0.000	0.964 0.000		-0.460 0.036	0.416 0.061	0.406 0.068	
MSWS-12 53.8 ± 8.4	-0.605 0.004	-0.546 0.01005	-0.460 0.036		-0.359 0.110	-0.550 0.0097	
VAS-balance 3.7 ± 2.0	0.446 0.043	0.419 0.059	0.416 0.061	-0.359 0.110		0.844 0.000	
VAS-walking 3.6 ± 2.1	0.456 0.038	0.412 0.063	0.406 0.068	-0.550 0.0097	0.844 0.000		

Correlations were found between different measures when comparing them using the Pearson correlation (Table 18). The most stable correlations through Baseline, Test 1 and Test 2 were found for the 6 min walk test that correlated at every testing with the 2 min walk test, 25-foot fast walk test and the subjective measurement of MSWS-12. Also, a strong correlation is found between the subjective measures of VAS. This supports the findings of the comparative analysis where all subjective measurements followed each other (*Chapter 6.1.9*). This is strengthened by the fact that by Test 2 also MSWS-12 correlated with VAS-walking.

The 2 min walk test and 25-foot fast walk test correlated with each other at every testing. But a correlation between 2 min walk test, 25-foot fast walk test and the subjective measure MSWS-12 could not be observed anymore at Test 1 or Test 2. This partly concurs with the observation made in the comparative analysis (*Chapter 6.1.9*) where a relation between the walk test and the subjective measures could not be found.

A new finding was the strong inverse correlation between objective walk test of 6 min and the subjective measurement of MSWS-12, strong in the sense that the correlation could be observed at each testing. This indicates that if a change is observed in either one of these measurements one can expect an inverse finding in the other.

6.2 Relations found between set goals, volume of rehabilitation, client's impression of change and the objectively measured walking capacity.

Two graphs have been made to illustrate the most essential test results for the secondary research question (Figures 8-9). Volume of rehabilitation (Figure 8) was calculated by including individual rehabilitation, group rehabilitation and autonomous training (See *Appendix 5*). The volume is presented as how many hours of rehabilitation the client received or performed per week between Baseline and Test 1 and between Test 1 and Test 2. The analyzing of the data was done as described in *Chapter 5.4*.

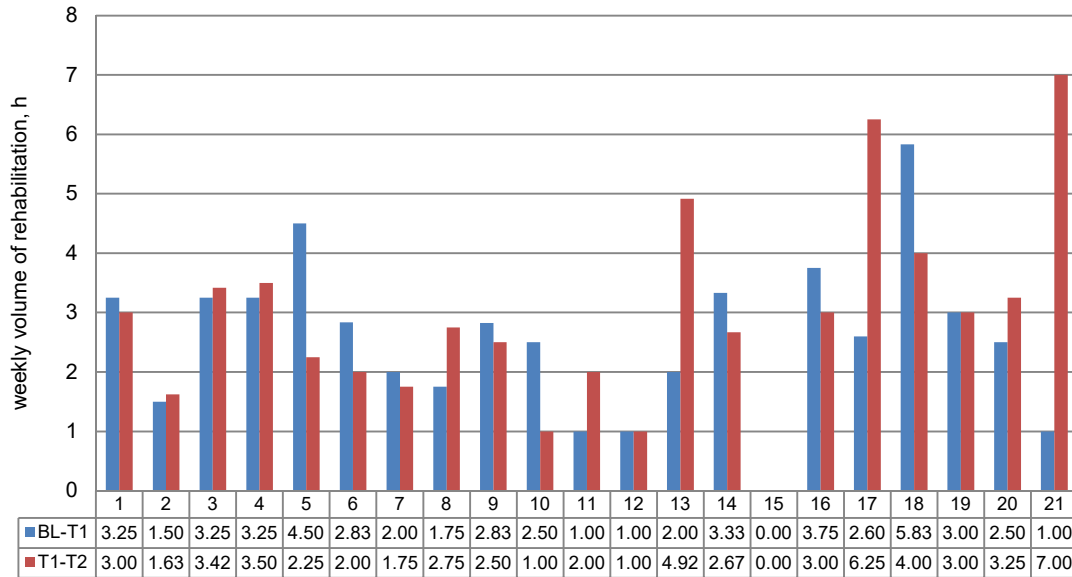


Figure 8. Combined individual weekly volume of rehabilitation between Baseline and Test 1 and Test 1 and Test 2, respectively.

The average change in walking test results was calculated from all test results combined as shown individually for every participating client in Figure 9. The results are presented in meters / min.

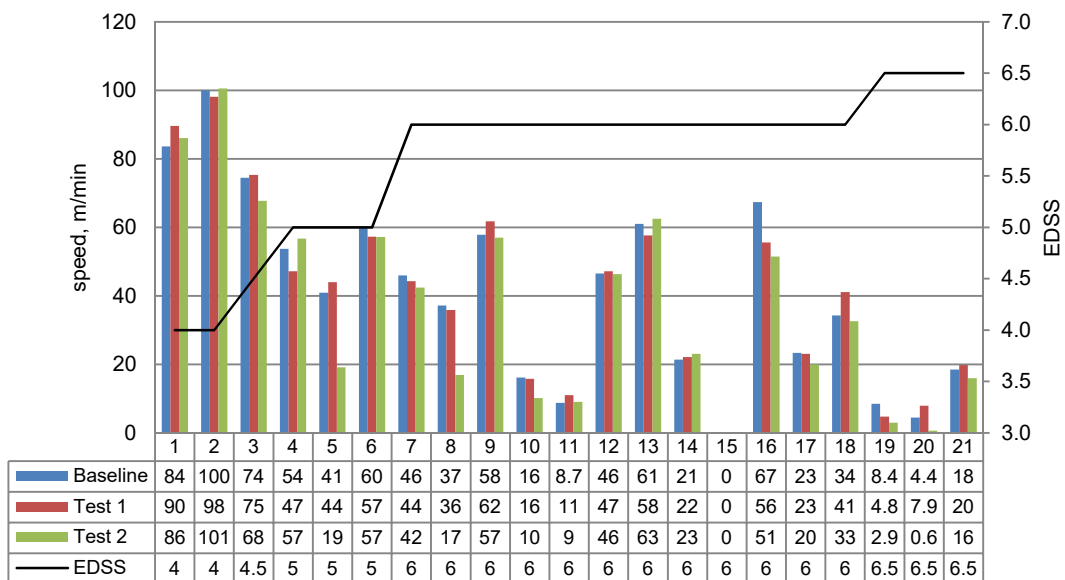


Figure 9. Combined individual walking test results.

6.2.1 Test 1 Results

In Table 19 all test results at Test 1 are shown. The results are divided into groups according to the chosen primary goal. Clients felt only minimal or no changes in walking.

Table 19. Results from Test 1.

Client	EDSS	Primary goal	weekly rehabilitation volume, h	average change in walking results between BL and T1, %	subjective IOC of walking
1	4	1	3.25	+7.3%	5
4	5	1	3.25	-12.0%	4
13	6	1	2.00	-5.5%	4
7	6	2	2.00	-3.8%	5
18	6	2	5.83	+20.0%	3
21	6.5	2	1.00	+6.9%	4
2	4	3	1.50	-1.9%	3
3	4.5	3	3.25	+1.1%	4
5	5	3	4.50	+7.5%	3
6	5	3	2.83	-4.8%	4
8	6	3	1.75	-3.4%	4
9	6	3	2.83	+6.7%	3
10	6	3	2.50	-2.5%	4
11	6	3	1.00	+25.6%	4
12	6	3	1.00	+1.6%	5
14	6	3	3.33	+3.6%	3
16	6	3	3.75	-17.5%	3
17	6	3	2.60	-1.6%	3
19	6.5	3	3.00	-43.5%	5
20	6.5	4	2.50	+80.3%	5

Primary goal: Improving balance

Client 1 perceives that walking has minimally improved which relates to the fact that also walk test results show an improvement. Clients 4 and 13 report no change in walking. However, test results have declined.

Primary goal: Improving walking

Client 7 reports minimally improved walking which is in contradiction to the decline in walking results. Client 18 perceives walking to have minimally worsened which is contradictory to the positive walk test results. Client 21 reports no change, the actual

change is measured positive with an increase in walking speed by 6.9%. No clear relation is seen for any client.

Primary goal: Maintenance of balance and walking

Clients 19 and 12 felt minimal improvement. This relates well to positive walk test results of client 12. There is no relation to be found for client 19 whose walk test results decline by 43.5%. Clients 3, 6, 8, 10 and 11 report no change. Only the walk test results of client 11 (+25.6%) deviate from this impression. Clients 2, 5, 9, 14, 16 and 17 report minimal change to the worse, which relates well with test results of clients 2 and 17. Results of client 16 are also negative but the decline is 17.5%. No relation can be found for clients 5, 9 and 14 as their walk test results are positive.

Primary goal: Other not related to balance and walking

The client reported that walking had minimally improved since Baseline. Nevertheless, walking test results improved by 80.3%.

In conclusion only 8 of 20 clients showed a relation, similarities between IOC and walk test results.

10 clients showed a decline in the walking test results and 10 an improvement. When comparing these results to the weekly amount of rehabilitation out of the 10 clients with the decline 3 received rehabilitation 3 hours or more / week. When comparing the 10 clients with the improvement 5 clients received rehabilitation 3 hours or more / week.

6.2.2 Test 2 Results

At Test 2, the same types of data were used. The results are presented in Table 20. After Test 1, the primary goal was set again.

Table 20. Results from Test 2.

Client	EDSS	Primary goal 1-4	weekly rehabilitation volume, h	average change in walking results between T1 and T2, %	subjective IOC of walking
13	6	1	4.92	+8.4%	3
7	6	2	1.75	-4.1%	5
9	6	2	2.50	-7.8%	5
11	6	2	2.00	-17.6%	4
12	6	2	1.00	-1.8%	3
16	6	2	3.00	-7.4%	6
21	6.5	2	7.00	-19.1%	5
1	4	3	3.00	-4.0%	7
2	4	3	1.63	+2.4%	5
3	4.5	3	3.42	-10.0%	5
4	5	3	3.50	+20.1%	3
5	5	3	2.25	-56.5%	6
6	5	3	2.00	-0.1%	5
8	6	3	2.75	-53.0%	4
10	6	3	1.00	-35.7%	6
14	6	3	2.67	+4.2%	4
17	6	3	6.25	-13.2%	5
18	6	3	4.00	-20.6%	5
19	6.5	3	3.00	-39.2%	6
20	6.5	4	3.25	-92.0%	7

Primary goal: Improving balance

Client 13 reports minimally worsened walking ability which is in contradiction to improved walking test results.

Primary goal: Improving walking

Clients 7, 9, 16, 21 perceive walking to have improved which is contradictory to the negative walk test results. Client 12 reports minimal change to the worse, which relates well with test results.

Primary goal: Maintenance of balance and walking

Twelve clients set their primary goal to maintenance of balance and walking. Clients 1, 4 and 17 had other goals at the first testing. Client 1 reports very much improved walking but walk test results show negative development. Eight clients feel their walking has improved but seven of them show declined walking ability. From this group, two out of 12 clients showed similarities between IOC and walk test results.

Primary goal: Other not related to balance and walking

The results for client 20 are contradictory (IOC: very much improved; walking ability based on walk tests: -92.0%).

In conclusion, out of the 20 clients presented here 3 showed a relation, similarities between IOC and walk test results.

16 clients showed a decline in the walking test results and 4 clients showed an improvement. 8 clients who showed a decline received 3 hours or more rehabilitation / week. 2 clients out of the 4 who showed an improvement received 3 hours or more of rehabilitation.

7 DISCUSSION

Relations were discovered when analyzing the evaluation of MS clients' with subjective self-report measures and objective performance based walking tests. Also clear correlations were found between some of the selected measures through statistical analysis.

The results from the comparative analysis show, for the primary research question in this study, that on average MS clients perceived their confidence measured with VAS deteriorating by Test 1 and improving by Test 2. This was strengthened by the fact that a correlation between the measures was observed at every testing with statistic calculations. The same trend could be seen with the results from the MSWS-12 questionnaire. A clear statistical correlation was observed at Test 2 between the MSWS-12 and VAS-walking. This shows a preliminary link between all three subjective measures as was detected in the comparative analysis. Strong statistical correlation between the VAS measurements was detected. The statistical analysis also showed a strong correlation between the objective measures at every testing.

According to Nilsagård et al. (2007 p. 140) and Goverover et al. (2005 p. 2306), objective and subjective measures provide valuable results to the evaluation of the rehabilitation. One of the most interesting findings in this study was the one between the 6 min walk test result and MSWS-12 score: a statistically relevant inverse correlation was observed at every testing. The finding indicates that if a therapist observes a change in either one of these measurements one can expect a similar, inverse finding in the other.

A trend could also be seen in the comparative analysis between the EDSS score and the objectively measured walking ability as they concurred with each other at Baseline, Test 1 and Test 2. EDSS is still a widely used and known measurement in clinical trials (Hobart et al. 2000 p. 1027-1035). The author of this study observed that this is an instrument that can be trusted and would use it again if needed in a future study. Also, the findings indicate that a therapist, when receiving a new client with MS, can take guidance from the EDSS score given by the neurologist.

The author of this study feels intrigued by how the relation between the objective walk tests and the subjective self-report measures, especially the VAS measurements, would have been, if the client could have had the chance to study their own earlier subjective responses. So that they could ask themselves the question: *“Do I really want to write down that I feel worse / better than before, is that really how I feel?”* What kind of impact would this have if the clients would have been given a chance to self-reflect?

The secondary research question was: what relations can be found between set goals, volume of rehabilitation, client’s impression of change and the objectively measured walking capacity? One of the strong points of this study was the timespan. Much changed in the data between Test 1 and Test 2, that would not have been detected otherwise. At Test 1, 8 of 20 clients showed a relation between impression of change and walk test results. But at Test 2, out of the 20 clients presented here only 3 showed similarities between IOC and walk test results. According to Stuijbergen et al. (2014 p. 2), in the beginning of treatment subjective self-reports can offer prognostic assessment of a person’s physical abilities. In this study the clients’ impression of change was more accurate at Test 1 than it was at Test 2, but not strong enough to make for a clear relation.

The relation between rehabilitation and walking capacity is complicated and many factors outside of rehabilitation influence the result. For example Huisinga et al. (2013 p.303) state that MS is the result of a progressive neurodegeneration. Therefore one can interpret that walking test results that remain stable between testings is positive and one can even argue that walking test results that decline more slowly because of rehabilitation is positive. The interpretation of rehabilitation was wide in this study and included many different forms of rehabilitation (single, group and autonomous rehabilitation) all which work and affect the rehabilitation process very differently. More specificity is needed in future research.

7.1 Review of the study

Inner validity has been enforced in this study by using a timeline analysis (Laitinen 1998 p. 65). Firstly a theoretical background with prior research concerning relations between subjective and objective measurements for persons with MS has been established and results can be compared to this. Secondly the fact that the study was made over a longer time period has made it possible to compare results over time, strengthening the validity.

Outer validity can be divided into two parts, comparability and transference (Laitinen 1998 p. 67). The author has gone to great lengths to keep this study accessible and has chosen to include all parts of the analyzing process, giving the reader all the tools to compare different parts of this study to each other as well as to others studies. Using well known and understood concepts and defining the most critical ones in the theoretical background was a part of accomplishing a stronger outer validity of this study.

Outer validity is something that case studies are easily critiqued of lacking. This is according to Yin (2006 p. 57-58) often because of the comparison with a survey study. Survey studies are built on statistical generalizations starting out with a correct sampling from a population. Case study is very different. According to Yin case studies should pursue analytical generalizations to a theory more in likeness with an experimental study. In this study relations between the objective and subjective tests were explored and in the conclusions the writer has drawn conclusions on a broader scale.

Reliability is the third and final quality demand for a case study. Reliability means that any other researcher could follow the steps taken in this study and come to the same results and conclusions (Yin 2006 p. 59). Study assembly and preparation are essential. Another important part of improving reliability of a case study is preserving original data, even to the point that the original data is accessible to other researchers when needed and also that a clear chain of events can be presented (Laitinen 1998 p. 72). The author has preserved all data and has it in such a form that every client's every single answer included in this study can be presented on demand.

Statistical analysis was also used to verify and strengthen the results from the comparative analysis (*Chapter 5*).

7.2 Conclusions

In light of these results this study so far concludes that when evaluating rehabilitation in Outpatient Rehabilitation Center Aksoni a therapist can rely on the fact that the objective measures presented here correlate well with each other. Similarly, the subjective measures relate with each other. These results were found by the comparative case study analysis as well as statistical analysis. The main finding of the comparative analysis was that results from subjective and objective measures differ significantly. For the most part, this is verified by statistical analysis. However, the statistical analysis showed that the MSWS-12 score can predict walking ability in some extent.

This study points out that it is not necessary to use every walking test presented here when evaluating a client, but to choose the one most appropriate and most fitting for the individual client. As the walking tests correlate, the therapist can rely on the fact that the findings would be similar for any walking test. The same can be said for the VAS reports. If the client has a bad day, which can occur quite often with MS, with fatigue being one of the most common symptoms (White & Dressendorfer 2004 p. 1077) or just does not wish to do a long walk test, the MSWS-12 results may be used to predict walking ability to some extent. The MSWS-12 subjective test is not physically demanding and can be done as often as needed. This saves the clients energy, but still provides valuable information about how the rehabilitation is proceeding.

Nilsagård et al. (2007 p. 140), Goverover et al.(2005 p. 2306) and Pugliatti et al. (2008 p.161) all promote the use of both subjective and objective methods of testing arguing that they complement each other. Each way of testing solely has weaknesses. The author of this study concurs as this study has concluded the same kind of findings. By examining results from subjective and objective measures in a one year timespan new findings were made, correlations discovered and patterns in the data over time explored that would otherwise not have been detected.

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APPENDIX 1

Short walk tests:

- * begin with administering the short walk tests
- * the short walk tests consist of two formats of the Timed 25-Foot Walk (T25FW):
 - trial 1 = T25FW at usual/comfortable speed (*usual speed should be done first*)
 - trial 2 = T25FW at fastest/maximal speed (*fastest speed should be done after usual speed*)
- * leave 1 minute rest in between the two trials, and 1 minute rest after the second trial before administering the long walk tests

For the T25FW, the subject should be directed to one end of a clearly marked 25-foot course (7,62 meters), defined on the floor or on the wall, and instructed to stand just behind the starting line (= **standing start**). Point out where the 25-foot course ends, then instruct the patient as follows:

- **trial 1:** *I'd like you to walk 25 feet at your own comfortable pace. Do not slow down until after you've passed the finish line. Ready? Go.*

- **trial 2:** *I'd like you to walk 25 feet as quickly as possible, but safely. Do not slow down until after you've passed the finish line. Ready? Go.*

Patients may use assistive devices when doing this task. Begin timing when the lead foot is lifted and crosses the starting line. The examiner should walk along with the patient as he/she completes the task. Stop timing when the lead foot crosses the finish line. The examiner should then record the subject's walk time to within 0.1 second, rounding as needed. The time limit is set to 3 minutes (180 seconds).

TIMED 25-FOOT WALK

Did patient wear an AFO?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Was assistive device used?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Assistive device used (<i>mark one</i>):			
<input type="checkbox"/> Unilateral Assistance	<input type="checkbox"/> Cane	<input type="checkbox"/> Crutch	
<input type="checkbox"/> Bilateral Assistance	<input type="checkbox"/> Cane	<input type="checkbox"/> Crutch	<input type="checkbox"/> Walker/Rollator

Trial 1

Time for 25-Foot Walk	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	seconds
For a complete trial, record any circumstances that affected the patient's performance:						
<hr/>						
<hr/>						
If trial was not completed (<i>mark one</i>):				Specify:		
<input type="checkbox"/>	Unable to complete trial due to physical limitations			⇒	<hr/>	
<input type="checkbox"/>	Other			⇒	<hr/>	

Trial 2

Time for 25-Foot Walk	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	seconds
For a complete trial, record any circumstances that affected the patient's performance:						
<hr/>						
<hr/>						
If trial was not completed (<i>mark one</i>):				Specify:		
<input type="checkbox"/>	Unable to complete trial due to physical limitations			⇒	<hr/>	
<input type="checkbox"/>	Other			⇒	<hr/>	

APPENDIX 2

Long walk tests:

- * after the execution of the short walk tests, long walk tests should be administered
- * the long walk tests consist of the 2-Minute Walk Test (2MWT) and 6-Minute Walk Test (6MWT)
- * the 2MWT and 6MWT should be randomly administered, by flipping a coin; e.g.:
heads = 2MWT ↔ tails = 6MWT
- * after flipping the coin, **please write down beneath which long test is administered first and which long test is administered second, as the same order should be kept at baseline testing and after the intervention period:**
 - long test 1 =
 - long test 2 =
- * **leave 15 minutes rest in between the two long tests, during which the MS Walking Scale and Visual Analogue Scales should be completed (see also page 9 + page 10)**
- * **during the performance of the 6MWT, please also record the distance after 2 and 3 minutes**

The instruction script of Goldman et al is adopted for the administration of the 2MWT and 6MWT (Goldman et al. Evaluation of the six-minute walk in multiple sclerosis subjects and healthy controls. *Mult Scler* 2008;14(3):383-90).

- 2MWT:

Mark a 30-meter walkway with taped lines/cones. Tell the patient: *The object of this test is to walk **as fast as possible** for 2 minutes. You will walk back and forth in this hallway. Two minutes is a long time to walk, so you will be exerting yourself. You should pivot briskly at the taped line/behind the cone at each end of the hallway and continue back the other way without hesitation. Now I'm going to show you. Please watch the way I turn without hesitation. Demonstrate by walking one lap yourself. Walk and pivot briskly at the taped line/around the cone.*

Assistive devices can be used while performing the 2MWT. *Are you ready to do that? I'm going to use this stopwatch and clipboard to keep track of the time and number of laps you complete. I will notify you of your time at 1 minute. Remember that the object is to walk **as fast and far as possible** for 2 minutes, but don't run or jog. Start now, or whenever you are ready.*

When the timer shows 1 minute remaining, tell the patient the following: *1 minute has passed, you have 1 minute to go.* Do not use other words of encouragement or body language to speed up. If the patient stops walking during the test, say this: *You are doing well. You should keep walking if you're able.* Do not stop the timer.

If the patient stops before the 2 minutes are up and refuses to continue (or you decide that he/she should not continue), wheel the chair over for the patient to sit on, discontinue the walk and note on the worksheet the distance, the time stopped and the reason for stopping prematurely.

When the timer is 15 seconds from completion, say this: *In a moment, I'm going to tell you stop. When I do, just stop right where you are and I will come to you.* When time is up, say this: *Stop!* Walk over to the patient, and hand a chair where he/she can sit on. Mark the spot where he/she stopped by placing a bean bag or a piece of tape on the floor. Note the subject's walking distance to within 1 meter.

1) Distance after 2 minutes (m):
2) Did the patient needed rest stops during the performance of the 2MWT? YES / NO If yes, how many rest stops? n=
3) Remarks , if any:

- 6MWT:

Mark a 30-meter walkway with taped lines/cones. Tell the patient: *The object of this test is to walk **as fast as possible** for 6 minutes. You will walk back and forth in this hallway. Six minutes is a long time to walk, so you will be exerting yourself. You should pivot briskly at the taped line/behind the cone at each end of the hallway and continue back the other way without hesitation. Now I'm going to show you. Please watch the way I turn without hesitation.* Demonstrate by walking one lap yourself. Walk and pivot briskly at the taped line/around the cone.

Assistive devices can be used while performing the 6MWT. *Are you ready to do that? I'm going to use this stopwatch and clipboard to keep track of the time and number of laps you complete. I will notify you of your time at 1 minute and every minute after that. Remember that the object is to walk **as fast and far as possible** for 6 minutes, but don't run or jog. Start now, or whenever you are ready.*

When the timer shows 5 minutes remaining, tell the patient the following: *1 minute has passed, you have 5 minutes to go.*

When the timer shows 4 minutes remaining, tell the patient the following: *2 minutes have passed, you have 4 minutes to go.*

When the timer shows 3 minutes remaining, tell the patient the following: *3 minutes have passed, you have 3 minutes to go.*

When the timer shows 2 minutes remaining, tell the patient the following: *4 minutes have passed, you have 2 minutes to go.*

When the timer shows only 1 minute remaining, tell the patient: *5 minutes have passed, you only have 1 minute left.* Do not use other words of encouragement or body language to speed up. If the patient stops walking during the test, say this: *You are doing well. You should keep walking if you're able.* Do not stop the timer.

If the patient stops before the 6 minutes are up and refuses to continue (or you decide that he/she should not continue), wheel the chair over for the patient to sit on, discontinue the walk and note on the worksheet the distance, the time stopped and the reason for stopping prematurely.

When the timer is 15 seconds from completion, say this: *In a moment, I'm going to tell you stop. When I do, just stop right where you are and I will come to you.* When time is up, say this: *Stop!* Walk over to the patient, and hand a chair where he/she can sit on. Mark the spot where he/she stopped by placing a bean bag or a piece of tape on the floor. Note the subject's walking distance to within 1 meter.

1) **Distance** after 2 minutes (m):

Distance after 3 minutes (m):

Distance after 6 minutes (m):

2) Did the patient needed **rest stops** during the performance of the 6MWT? **YES / NO**

If yes, how many rest stops? **n=**

During which minute the first rest stop was taken?.....**minute**

3) **Remarks**, if any:

APPENDIX 3

MS Walking Scale (MSWS-12);

The MSWS-12 needs to be completed by the participant;

- These questions ask about limitations to your walking due to MS **during the past 2 weeks**
- For each statement, please circle the one number that best describes your degree of limitation
- **Please answer all questions** even if some seem rather similar to others, or seem irrelevant to you

In the past two weeks, how much has your MS ...	Not at all	A little	Moder- ately	Quite a bit	Ex- tremely
1. Limited your ability to walk?	1	2	3	4	5
2. Limited your ability to run?	1	2	3	4	5
3. Limited your ability to climb up and down stairs?	1	2	3	4	5
4. Made standing when doing things more difficult?	1	2	3	4	5
5. Limited your balance when standing or walking?	1	2	3	4	5
6. Limited how far you are able to walk?	1	2	3	4	5
7. Increased the effort needed for you to walk?	1	2	3	4	5
8. Made it necessary for you to use support when walking indoors (e.g., holding on to furniture, using a stick, etc.)?	1	2	3	4	5
9. Made it necessary for you to use support when walking outdoors (e.g., using a stick, a frame, etc.)?	1	2	3	4	5
10. Slowed down your walking?	1	2	3	4	5
11. Affected how smoothly you walk?	1	2	3	4	5
12. Made you concentrate on your walking?	1	2	3	4	5

Please check that you have circled ONE number for EACH question

Items are summed to generate a total score: /60 (range 12-60)

Visual Analogue Scales (VAS);

The following VAS need to be marked by the participant;

1) How confident have you been in your walking during the past week?



2) How confident have you been in your balance during the past week?



APPENDIX 4

Impression of Change:

→ Participant's impression of change

(needs to be completed by the participant, **JUST BEFORE THE POST-ASSESSMENT**)

Compared to before the intervention period/before starting rehabilitation at this center, how would you rate your health in general now?

- | | |
|-----------------------|-----------------------|
| 1) very much worse | <input type="radio"/> |
| 2) much worse | <input type="radio"/> |
| 3) minimally worse | <input type="radio"/> |
| 4) no change | <input type="radio"/> |
| 5) minimally improved | <input type="radio"/> |
| 6) much improved | <input type="radio"/> |
| 7) very much improved | <input type="radio"/> |

Compared to before the intervention period/before starting rehabilitation at this center, how would you rate your walking now?

- | | |
|-----------------------|-----------------------|
| 1) very much worse | <input type="radio"/> |
| 2) much worse | <input type="radio"/> |
| 3) minimally worse | <input type="radio"/> |
| 4) no change | <input type="radio"/> |
| 5) minimally improved | <input type="radio"/> |
| 6) much improved | <input type="radio"/> |
| 7) very much improved | <input type="radio"/> |

→ Therapist's impression of change

(needs to be completed by the treating physiotherapist, **JUST BEFORE THE POST-ASSESSMENT**)

Compared to before the intervention period/before starting rehabilitation at this center, how would you rate the participant's health in general now?

- | | |
|-----------------------|-----------------------|
| 1) very much worse | <input type="radio"/> |
| 2) much worse | <input type="radio"/> |
| 3) minimally worse | <input type="radio"/> |
| 4) no change | <input type="radio"/> |
| 5) minimally improved | <input type="radio"/> |
| 6) much improved | <input type="radio"/> |
| 7) very much improved | <input type="radio"/> |

Compared to before the intervention period/before starting rehabilitation at this center, how would you rate the participant's walking now?

- | | |
|--------------------|-----------------------|
| 1) very much worse | <input type="radio"/> |
| 2) much worse | <input type="radio"/> |
| 3) minimally worse | <input type="radio"/> |

- 4) no change
- 5) minimally improved
- 6) much improved
- 7) very much improved

APPENDIX 5

Identification of REHABILITATION CONTEXT *short questionnaire at individual patient level*

This questionnaire aims to make an inventory of the ‘black box’ of the physical rehabilitation program that is applied on patients participating in the study investigating responsiveness of walking outcome measures.

Please answer the following questions below regarding the physical rehabilitation program that your individual patient attended.

In this first multicenter study also encompassing content of the physical rehabilitation program, we only focus on sessions guided or supervised by physiotherapists and sport/fitness instructors.

Please indicate your profession:

1) Physiotherapist	
2) Sport or fitness instructor	
3) Other (please specify)	

1. SETTING of physical rehabilitation

Please indicate the setting where the patient performs/receives physical rehabilitation.

Mark ‘1’ for the primary setting.

Maximally two settings can be marked in case of a combined setting.

(if the patient is transferred, for example stayed overnight in the rehabilitation center during 4 weeks, and is then coming to the center from a hotel or his home, please perform a post-measurement at the time of the transfer and consider starting up a new file when the patient is at the new setting)

1) HOSPITAL with overnight stay	
2) NEUROLOGICAL REHABILITATION CENTER with overnight stay	
3) HOSPITAL without overnight stay	
4) NEUROLOGICAL REHABILITATION CENTER without overnight stay	
5) Fitness center	
6) Research facility (e.g. at the university)	
7) Private PT practice in the community	
8) Community center (MS Society, sports facilities other than fitness center,...)	
9) Home of the patient	
10) Other (please specify)	

Did the patient receive an individual exercise program to be performed on their own, outside therapy time?

Mark 1=yes, 0=no

Did the patient also receive weekly therapy or counselling from other professionals in the multidisciplinary team?

- Occupational therapy (mark 1=yes, 0=no)
- Psychology (mark 1=yes, 0=no)

- Nurse (mark 1=yes, 0=no)

Did the patient receive/perform a substantial amount of physical rehabilitation by other professionals than yourself (and the multidisciplinary team) during the intervention period?

(for example, you may score the patient regarding the sessions that are provided in the physiotherapy department, but the patient may also weekly participate in a swimming group)

1=yes, 0=no

If yes, please specify type here as well as training volume:.....;(minutes/week)

2. Primary GOAL of physical rehabilitation

What was the primary goal of the physical rehabilitation program provided by you?

1) Improving balance	
2) Improving walking capacity	
3) Maintenance of balance and walking	
4) Other, not related to balance and walking	

Mark '1' for the most correct answer, others are marked as '0'.

Please choose only one answer.

3. DURATION of physical rehabilitation

Please write the appropriate numerical score for each category below:

1) Total number of weeks	
2) *Individual therapy (yes=1, no=0)	
3) Average number of individual sessions / week	
4) Averaged duration of individual session (minutes)	
5) Total number of individual sessions	
6) Group therapy (yes=1, no=0)	
7) Average number of group sessions / week	
8) Averaged duration of group session (minutes)	
9) Total number of group sessions	
10) **Autonomous therapy (yes=1, no=0)	
11) Average number of autonomous sessions / week	
12) Averaged duration of autonomous session (minutes)	
13) Total number of autonomous sessions	

**Individual therapy is defined as therapy with a 1:1 ratio between therapist and patient. For example, fitness training performed in a group with 1 therapist is considered as group therapy, even if the fitness training is individualized and supervised.*

***Autonomous therapy sessions can be ticked for autonomous and individual therapy execution by the patient, outside a group. For example, fitness training that is performed individually (outside a group setting, the individual comes at his/her own preference).*

4. CONTENT of physical rehabilitation

In the following, we aim to identify the main therapeutic approaches that were applied during the intervention.

Please mark:

- which interventions and therapeutic approaches you applied for this patient

- if applied, how important you consider them by marking '1' for interventions and therapies you consider as primary (most commonly used) and '2' for secondary therapies and interventions (occasionally used)
 For data processing, it is important that you prioritize. It would be expected that typically 1 up to maximally 3 interventions and approaches have been primarily applied in this individual patient.

THERAPEUTIC APPROACH	Applied? (1=yes, 0=no) <i>5 choices max</i>	Importance? (1=primary, 2= secondary)
1) Passive mobilisation/stretching (by therapist)		
2) Self-stretching		
3) Muscle strengthening with therapist's resistance and/or by use of own body weight		
4) Resistance training, with external equipment		
5) Aerobic training		
6) Combined resistance and aerobic training		
7) Balance training		
8) Gait training – functional approach		
9) Gait training – treadmill (or alike)		
10) Frenkel's exercises		
11) Dual tasking		
12) Vojta reflex locomotion		
13) Constraint-induced movement therapy		
14) Proprioceptive neuromuscular facilitation		
15) Rood		
16) Petö concept		
17) Perfetti concept		
18) Bobath concept / neurodevelopmental treatment		
19) Motor learning / task-specific functional exercises		
20) Conductive education programme		
21) Other (please specify)		

APPENDIX 6

Kurtzke Expanded Disability Status Scale (EDSS)

- 0.0 - Normal neurological exam (all grade 0 in all Functional System (FS) scores*).
- 1.0 - No disability, minimal signs in one FS* (i.e., grade 1).
- 1.5 - No disability, minimal signs in more than one FS* (more than 1 FS grade 1).
- 2.0 - Minimal disability in one FS (one FS grade 2, others 0 or 1).
- 2.5 - Minimal disability in two FS (two FS grade 2, others 0 or 1).
- 3.0 - Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade 2, others 0 or 1) though fully ambulatory.
- 3.5 - Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3 (others 0 or 1) or five grade 2 (others 0 or 1).
- 4.0 - Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1), or combination of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 500 meters.
- 4.5 - Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterized by relatively severe disability usually consisting of one FS grade 4 (others or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 300 meters.
- 5.0 - Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (e.g., to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combinations of lesser grades usually exceeding specifications for step 4.0).
- 5.5 - Ambulatory without aid for about 100 meters; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0).

- ❑ 6.0 - Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).
- ❑ 6.5 - Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).
- ❑ 7.0 - Unable to walk beyond approximately 5 meters even with aid, essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day; (Usual FS equivalents are combinations with more than one FS grade 4+; very rarely pyramidal grade 5 alone).
- ❑ 7.5 - Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; May require motorized wheelchair; (Usual FS equivalents are combinations with more than one FS grade 4+).
- ❑ 8.0 - Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms; (Usual FS equivalents are combinations, generally grade 4+ in several systems).
- ❑ 8.5 - Essentially restricted to bed much of day; has some effective use of arm(s); retains some self-care functions; (Usual FS equivalents are combinations, generally 4+ in several systems).

(Kurtzke 1983 and Haber & LaRocca 1985)

- ❑ 9.0 - Helpless bed patient; can communicate and eat; (Usual FS equivalents are combinations, mostly grade 4+).
- ❑ 9.5 - Totally helpless bed patient; unable to communicate effectively or eat/swallow; (Usual FS equivalents are combinations, almost all grade 4+).
- ❑ 10.0 - Death due to MS.

*Excludes cerebral function grade 1.

Note 1: EDSS steps 1.0 to 4.5 refer to patients who are fully ambulatory and the precise step number is defined by the Functional System score(s).

EDSS steps 5.0 to 9.5 are defined by the impairment to ambulation and usual equivalents in Functional Systems scores are provided.

Note 2: EDSS should not change by 1.0 step unless there is a change in the same direction of at least one step in at least one FS.