

Physiotherapy and professional clinical guidance in an out-patient clinic for people with multiple sclerosis

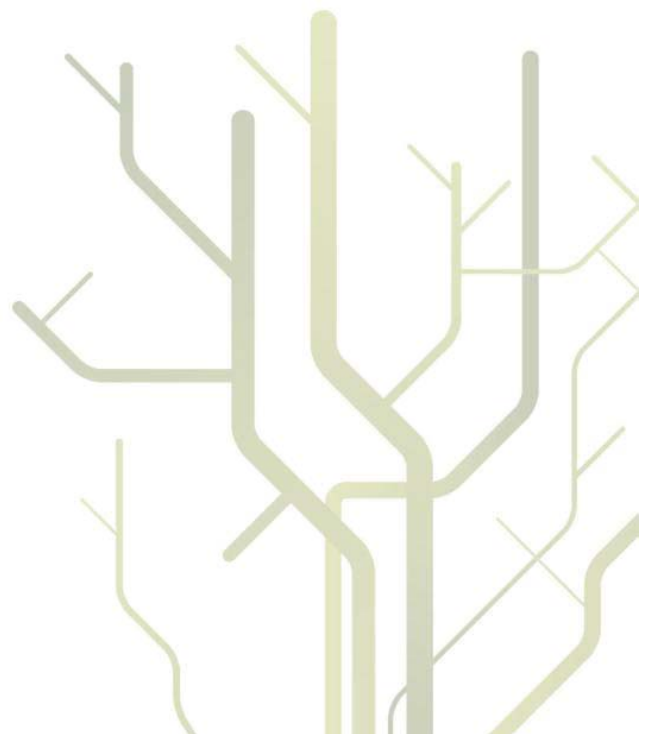
Body and movement in sense making and professional development



Britt Normann

A dissertation for the degree of Philosophiae Doctor

March 2013



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Scientific environment

This thesis was performed under supervision at the Department of Health and Care Sciences, Faculty of Health Sciences, University of Tromsø and the Nordland Hospital Trust, Bodø.

The study was conducted at the out-patient clinic for people with multiple sclerosis at Nordland Hospital Trust, Bodø.



NORDLANDSSYKEHUSET
NORDLÁNDA SKIHPPIJVIESSO

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Abstract

Multiple sclerosis (MS) is the leading cause of neurological disability in young people in industrialised countries. The disease leads to a variety of symptoms that cause difficulties in a person's activities of daily living (ADL); movement disturbances are one of the major problems. The traditional in-patient care for these people has been replaced, to a large extent, with treatment in out-patient (OP) clinics in hospitals. Some of these clinics provide follow-up from a specialist in neurological physiotherapy (oPT); a service in which single sessions are offered on a regular basis and complemented by optional professional clinical guidance of community physiotherapists (cPTs). Limited knowledge exists regarding physiotherapy in these settings.

The overall aim of this study was to derive new knowledge from people with MS' (PwMS') and cPTs' experiences from single sessions of physiotherapy and clinical guidance in an OP clinic to explore the theoretical framework for neurological physiotherapy. Focus was directed to PwMS's experiences and satisfaction regarding the process and potential short-term outcomes of care, the significance of perceptions of movement in this process, and what cPTs consider to be significant elements in professional clinical guidance.

The study contains three parts, including quantitative and qualitative methods in a triangulation design. A survey of 72 PwMS was performed, using the Outpatient Experience Questionnaire (OPEQ) to record patient satisfaction, and the Patient Global Impression of Change (PGIC) and the Borg's Rating Scale of Perceived Exertion (BRSPE) were used to investigate perceived short-term changes in relevant ADL (Paper I). Qualitative research interviews supplemented by non-participating observations were performed with a nested and purposive sample of 12 PwMS (Paper II) and 9 cPTs who received clinical guidance for their own patients (Paper III). A theme based content analysis was performed using phenomenology of the body as an overall framework, complemented by neurosciences and practice knowledge. Finally, an analysis of the results from papers I-III was performed.

The results from the OPEQ showed strong patient satisfaction with the physiotherapy regarding both interpersonal and clinical skills (mean 9.4, SD 1.0, best score 10) independent

of ambulatory status, gender, or age. Participation through body and movement played an essential role in the inter-subjective process between the oPT and PwMS. Expressions and perceptions of movement, and physical interaction (handling) appeared to be significant for deepening the communication process; allowing for pre-reflective information to be exchanged and integrated into the reflective considerations which deepened the PwMS's insights regarding their own movement problems.

The results from the PGIC indicated perceived short-term improvement in standing up/sitting down and walking for ca. 60 % of the patients, no deteriorations, and the BRSPE showed a significantly lower perception of exertion during these activities after the consultation. Such improvements in performance of movement is understood as short term changes in embodied intentionality, enhancement of the patient's sense of ownership and sense of agency; hence, an improved ability to engage in ADL. Perceptions of change in movement appeared as a strong element in PwMS's sense-making process regarding their own movement problems. These perceived changes, contextualised in the oPT's explanations that interlinked the changes with basic elements in balance and walking or other relevant ADL, deepened the PwMS's insights regarding their own limitations and possibilities.

PwMS reported that guidance in tailored self-assisted exercises is vital. The relevance of the exercise seemed to be augmented through implementation of movements which they during the session had experienced improvement from performing. Hands-on guidance supplemented by verbal instruction appeared to enable the patient to actively perform exercises that explore new and more optimal movement strategies, but independent replication may be difficult.

Participation in authentic movement analysis of a familiar patient with whom hands-on facilitation techniques were used appeared to augment the development of active elements in practice knowledge and, particularly, in the cPTs' clinical reasoning skills. Changes in quality of movement that evolved during explorative treatment in clinical guidance sessions deepened the cPTs' sense making in the particular situation and general aspects of relevance for physiotherapy to similar patients. Observing how improvement or decline in quality of movement was obtained in authentic clinical settings reinforced reflections in practice and on

practice and provided access to vital context-bound elements in practice knowledge, which are only available through first-hand experience of the particular actions.

Professional guidance through observation and discussion seemed insufficient with regards to the development of handling skills. Previous practice knowledge regarding neurological physiotherapy may determine what the cPTs gain from the guidance session as concerns implementation of the advice in subsequent treatment. Complementary ways of learning involving supervision of the cPTs' actions may be necessary. A strengthening of the cPTs' perspectives as a basis for professional guidance and as a structure for mutual collaboration is recommended.

The present thesis emphasises the significance of perceptions of body and movement in sense making for PwMS to gain a deepened insight regarding their own movement problems and opportunities regarding ADL and also in professional development of cPTs. Furthermore, clinical settings as arenas for professional guidance are highlighted; providing access to other aspects of professional competency than words alone. These findings should be considered when information “packages” and physiotherapy services to PwMS and continued professional development programs are established. Moreover, an exploration of phenomenology of the body as an overall foundation for neurological physiotherapy, providing a first-person conception of the body, is presented. These conceptions allow for an understanding of the physical interaction between the physiotherapist and the patient as a form of communication similar to verbal and non-verbal elements (gesticulations, etc.) and allows for a possible expanded comprehension of physical handling and inter-subjectivity in physiotherapy. The phenomenological ambiguousness of the body, simultaneously being and having a body or simultaneously a body-as-subject and a body-as-object, creates a space for integrating relevant neurobiological, muscular, and movement sciences and the possibility of complementing this theory with practice knowledge. This incipient extension of the theoretical foundation for neurological physiotherapy requires further development.

Sammendrag

Multipel sklerose (MS) er en ledende årsak til nevrologisk betinget funksjonsproblemer hos unge voksne i den industrialiserte del av verden. Sykdommen gir ulike symptomer som medfører problemer i dagliglivets aktiviteter (ADL), og bevegelsesforstyrrelser er et av hovedproblemene. Tradisjonelle innleggelse i sykehus er for en stor del erstattet av behandling i MS-poliklinikker. Enkelte av disse tilbyr nevrologisk fysioterapi (polF); en tjeneste hvor regelmessige enkeltkonsultasjoner tilbys og komplementeres med tilbud om klinisk veiledning til kommunefysioterapeuter (komF). Det eksisterer begrenset kunnskap om fysioterapi i MS-poliklinikker.

Overordnet mål for studien var å utvikle ny kunnskap basert på personer med MS' (PmMS') og komF's erfaringer med fysioterapikonsultasjoner og klinisk veiledning i MS-poliklinikk, samt å videreutvikle et teoretisk fundament for nevrologisk fysioterapi. Fokus var rettet mot PmMS' grad av tilfredshet, potensielle endringer i bevegelseskvalitet, betydningen av persepsjon av bevegelse for utvikling av innsikt og hva komF vurderer som sentrale elementer i profesjonell klinisk veiledning.

Studien inkluderer tre deler, og omfatter kvantitative og kvalitative metoder i et trianguleringsdesign. En spørreundersøkelse blant 72 PmMS ble gjennomført ved hjelp av PassOpp-Pol spørreskjema og to selvrapporteringsskjema; Pasientens overordnede opplevelse av endring (PGIC) og Borgs skala for opplevd anstrengelse (BRSPE) (Artikkel I). Kvalitativt forskningsintervju supplert med ikke-deltagende observasjon ble gjennomført med et strategisk utvalg på 12 PmMS (Artikkel II) og 9 komF som deltok på klinisk veiledning med egne pasienter (Artikkel III). Temabasert innholdsanalyse ble gjennomført med kroppsfenomenologi utfyllt med nevrobiologi og praktisk kunnskap som teoretiske perspektiver. Analyse av resultatene fra de tre artiklene ble gjennomført til slutt.

Resultatene fra PassOpp-pol viste svært høy tilfredshet med fysioterapi når det gjelder mellommenneskelige og kliniske ferdigheter (Gj.sn. 9.4, St.avvik 1.0; beste score er 10) uavhengig av funksjonsnivå, alder og kjønn. Deltakelse gjennom kropp og bevegelse spilte en

vesentlig rolle i den intersubjektive prosessen mellom polF og PmMS. Uttrykk og erfaringer formidlet gjennom kroppen fremstod som avgjørende, da dette bidro til at pre-refleksiv informasjon ble utvekslet og integrert i den verbale kommunikasjonen; noe som bidro til å gi PmMS utvidet innsikt i egen situasjon.

PGIC viste bedring for ca. 60 % av pasientene i gange og reise/sette seg, og BRSPE viste signifikant lavere selvopplevd anstrengelse i disse aktivitetene etter konsultasjonen. Slike bedringer i bevegelsesutførelse forstås som forbigående endringer i kroppslig intensjonalitet og styrking av pasientens følelse av eierskap og kontroll over egen bevegelse; og potensiell endring i ADL. Opplevelse av endring (positive og negative) i bevegelseskvalitet fremstod som vesentlig for å få økt innsikt i egne bevegelsesproblemer. Disse erfarte og observerte bevegelsesendringene, utfylt med polF's forklaringer, hvor endringene ble relatert til grunnleggende forutsetninger for balanse og gange eller andre relevante ADL, gav pasientene utvidet innsikt i egne muligheter og begrensninger.

Pasientene vurderte veiledning i tilpasset egentrening som vesentlig. Øvelsenes relevans ble forsterket ved implementering av bevegelser som pasienten i løpet av konsultasjonen hadde erfart førte til bedring i bevegelseskvalitet. Veiledning gjennom polF' bruk av hender supplert med verbal instruksjon gjorde det mulig for pasienten å utføre øvelser med optimale bevegelsesstrategier, men gjentakelse på egen hånd ble rapportert å være vanskelig. Videre oppfølging synes nødvendig.

Deltakelse i bevegelsesanalyse av en kjent pasient hvor polF brukte "hands-on" fasiliteringsteknikker i utforskning av potensiale for bedring syntes å fremme utvikling av aktive elementer i praktisk kunnskap, og spesielt komF' ferdigheter i klinisk resonnering. Endringer i bevegelseskvalitet som fremkom gjennom utprøving av behandling i veiledningstimen gav utvidet innsikt for komF i forhold til den aktuelle pasienten og generelle aspekter av relevans for fysioterapi til lignende pasienter. Observasjon av hvordan bedring eller forverring i bevegelseskvalitet ble oppnådd i autentisk praksis forsterket komF's refleksjon i og over praksis og gav tilgang til vesentlige kontekstavhengige elementer i

praktisk kunnskap som bare er tilgjengelige via førstehånds erfaring med de aktuelle handlingene.

Profesjonell veiledning gjennom observasjon og diskusjon synes å være utilstrekkelig når det gjelder utvikling av håndteringsferdigheter. Tidligere erfaring i nevrologisk fysioterapi synes vesentlig for komF's utbytte av veiledningen når det gjelder implementering i påfølgende behandling. Komplementære læringsarenaer som inneholder veiledning mens komF utfører handlingene synes nødvendig. Styrking av komF's perspektiver i profesjonell veiledning og struktur for gjensidig informasjonsutveksling anbefales.

Denne avhandlingen vektlegger betydningen av persepsjon av kropp og bevegelse som en vesentlig del av utvikling av innsikt i egne bevegelsesproblemer og muligheter knyttet til ADL for PmMS, og i profesjonell utvikling av komF. Videre løftes kliniske situasjoner frem som arena for utvikling og formidling av kompetanse, hvor andre sider ved kunnskap enn de som formidles gjennom ord alene synliggjøres. Disse funnene bør vurderes når informasjonsprogram for PmMS og kompetanseoppbyggingsprogram for komF etableres. Videre er kroppsfenomenologi som et overordnet teoretisk grunnlag for nevrologisk fysioterapi presentert. Denne forståelsen gir en førstepersons forståelse av kroppen og åpner for å se fysisk interaksjon mellom fysioterapeuten og pasienten som en form for kommunikasjon på linje med verbale og non-verbale (gestikulering, blikk osv.). Det åpnes dermed for en mulig utvidet forståelse av fysisk interaksjon (hands-on) og intersubjektivitet i nevrologisk fysioterapi. Den fenomenologiske tvetydigheten til kroppen, samtidigheten i å være og ha en kropp, kroppen-som-subjekt og kroppen-som-objekt, skaper rom for integrering av relevant nevro- og muskelbiologi, bevegelsesvitenskap og teori om praktisk kunnskap. Denne begynnende utvidelse av det teoretiske grunnlaget for nevrologisk fysioterapi bør videreutvikles.

List of publications

Paper I

Normann B, Moe S, Salvesen R, Sørgaard KW: *Patient satisfaction and perception of change following single physiotherapy consultations in a hospital's outpatient clinic for people with multiple sclerosis*. *Physiotherapy Theory and Practice*, 2011, Early Online, 1–11 Copyright © Informa Healthcare USA, Inc. ISSN: 0959-3985 print/1532-5040 online DOI: 10.3109/09593985.2011.574782

Paper II

Normann B, Sørgaard KW, Salvesen R, Moe S: *Contextualized perceptions of movement as a source of expanded insight: People with multiple sclerosis' experience with physiotherapy*. *Physiotherapy Theory and Practice*, Early Online: 1–12, 2012 Copyright © Informa Healthcare USA, Inc. ISSN: 0959-3985 print/1532-5040 online DOI: 10.3109/09593985.2012.698717

Paper III

Normann B, Sørgaard KW, Salvesen R, Moe S: *Clinical guidance for community physiotherapists treating people with MS: Professional development and continuity of care*. Submitted, *Physiotherapy Research International*; in review.

Abbreviations

MS	Multiple sclerosis
PwMS	People with multiple sclerosis
OP clinic	Out-patient clinic
CNS	Central nervous system
ADL	Activities of daily living
RR-MS	Relapsing remitting multiple sclerosis
SP-MS	Secondary progressive multiple sclerosis
PP-MS	Primary progressive multiple sclerosis
SO	Sense of ownership
SA	Sense of agency
cPT	Community physiotherapist
oPT	Out-patient clinic physiotherapist
EDSS	European Disability Status Scale
OPEQ	Out-Patient Experience Questionnaire
PGIC	Patient Global Impression of Change
BRSPE	Borg's Rating Scale of Perceived Exertion
NICE	National Institute of Health and Clinical Excellence
MSS	Multiple Sclerosis Society
EMSP	European Multiple Sclerosis Platform
CPD	Continued Professional Development
ICF	International Classification of Disability and Function

1. Introduction

Multiple sclerosis (MS) is the leading cause of neurological disability in young people in industrialised countries Myhr et al. (2001). Norway, along with most of northern Europe, is a high-risk area with an incidence of approximately 5-8 cases per 100 000 people and a prevalence of 150-170 cases per 100 000 people (Myhr, 2010). Nordland County, where the current study was conducted, is a medium-risk area for MS, with an incidence of 5.1 cases per 100 000 people and a prevalence of 105.6 cases per 100 000 people (Alstadhaug, Olavsen, & Salvesen, 2005). The disease leads to a variety of symptoms that cause difficulties in the persons' activities of daily living (ADL); movement disturbances constitute one of the major problems. Physiotherapy is a recommended service (European Multiple Sclerosis Platform [EMSP], 2012; National clinical guideline for diagnosis and management in primary and secondary care [NICE], 2004) and is commonly used by people with MS (PwMS) (K. Gottberg et al., 2008; Skovgaard et al., 2012). Optimising participation in ADL through improvement of body functions and activities as described in the International Classification of Health and Disability ¹(ICF) (World Health Organization [WHO], 2001) are key targets of physiotherapy for PwMS in conjunction with information and encouragement to self-manage throughout the course of the disease (Multiple Sclerosis Society [MSS], 2004; NICE, 2004).

The health care for PwMS is characterised by simultaneous long-time use of services in the hospitals and in the communities (K. Gottberg et al., 2008; Helse Nord, 2007). In Norway, as in many European countries, physiotherapy is mainly provided to PwMS by community physiotherapists (cPTs), who are rarely specialists in the neurological field (Norsk fysioterapeut forbund [NFF], 2012a). The traditional in-patient care for these people, to a large extent, has been replaced with treatment in out-patient (OP) clinics in the hospitals. These clinics, in which most of the medical treatment occurs (NICE, 2004; Solari et al., 2007), provide multidisciplinary services. Although physiotherapy is a widely perceived need among PwMS (MacLurg et al., 2005) and is recommended (NICE, 2004), the availability and content of physiotherapy services in OP clinics for PwMS vary. In Norway, physiotherapy is usually integrated into the multidisciplinary management courses for PwMS, and individual physiotherapy consultations may be conducted upon request from the neurologists at the OP

¹ International Classification of Health and Disability: Health Condition is dependent of interactions between Body functions and Structures (impairments), Activities and Participation that is influenced by Environmental Factors as well as Personal Factors (WHO, 2001).

clinic. However, some of these clinics provide a more systematic physiotherapeutic follow-up starting after the establishment of the diagnosis and continuing throughout the course of the disease; for this service, single sessions are offered on a regular basis and are complemented by optional professional clinical guidance of cPTs.

Based on PwMS's needs for information and follow-up regarding movement disturbances (EMSP, 2012; NICE, 2004) and the recent focus on collaboration between the different health care levels to secure continuity and quality of care (EMSP, 2012; Guthrie, Saultz, Freeman, & Haggerty, 2008; Haggerty et al., 2003; Helse- og omsorgstjenesteloven, 2011; Helse Nord, 2007), it is useful to know what PwMS gain from single sessions of specialised physiotherapy in OP clinics. Furthermore, the lack of competency in neurological physiotherapy among cPTs (NFF, 2012a), the hospitals' responsibility for guidance of community health care workers (Helse- og omsorgstjenesteloven, 2011; Helse-og omsorgsdepartementet [HOD], 2011), and an international focus on Continued Professional Development (CPD) (French & Dowds, 2008; NFF, 2012b) indicate the importance of investigating what professional clinical guidance of cPTs in these clinics may imply for those undergoing this service. So far, professional guidance of authorised physiotherapists in clinical settings has not been widely studied.

Research regarding physiotherapy for PwMS indicates an effect of various approaches (Beer, Khan, & Kesselring, 2012; Hogan & Coote, 2009; Wiles, 2008; Wiles et al., 2001), including growing evidence in support of strength training (Andreasen, Stenager, & Dalgas, 2011; De Souza-Teixeira et al., 2009; Kjølhede, Vissing, & Dalgas, 2012; Rietberg, Brooks, & Kwakkel, 2011) and fitness-training (Dalgas, Ingemann-Hansen, & Stenager, 2009; Heesen, Romberg, Gold, & Schultz, 2006; Sutherland, Andersen, & Stooove, 2007). Studies based on PwMS's experiences with physiotherapy in various settings report strength training as a feasible option for some patients (Dodd, Taylor, Denisenko, & Prasad, 2006), the need for rehabilitation and counselling (Gillanders, Murphy, & Crosbie, 2006; Ytterberg, Johansson, Gottberg, Holmqvist, & von Koch, 2008) and the importance of coping strategies (Lode et al., 2007), including physical activity (Plow, Resnik, & Allen, 2009). Patient satisfaction is often used as a quality measurement in health care research (Lian & Wilsgaard, 2005; Sitzia & Wood, 1997), but this factor has been less investigated in physiotherapy (Hills & Kitchen,

2007a) and, in particular, regarding PwMS. Research focusing on authentic practice and the patients' perspectives regarding physiotherapy in the hospitals' OP clinics for PwMS is sparse.

Body and movement are fundamental focuses in physiotherapy, and researchers have requested investigations of the inherent theoretical concepts regarding these components to further develop clinical practice and theory in physiotherapy (Broberg et al., 2003; De Souza, 1998; B. E. Gibson, Nixon, & Nicholls, 2010; Nicholls & Gibson, 2010). As an experienced physiotherapist in the neurological field, having worked both in the specialist and the primary health care settings and in postgraduate education of physiotherapists, I agree that there is a need to theoretically anchor more of the complexity in clinical practice in physiotherapy.

This thesis addresses single sessions of physiotherapy in hospitals' OP clinics for PwMS and the professional guidance of cPTs. The study investigates PwMS's satisfaction with the service and their perceptions of change in motor performance following these sessions using a questionnaire and self-reporting measurements. Furthermore, the focus in this thesis is directed toward an in-depth exploration of the role of the body and perceptions of movement in PwMS's process of gaining insight into their own situation, and towards investigation of cPTs' experiences following professional clinical guidance, using qualitative interviews and observations. The overall aim of the thesis was to provide a scientific basis for physiotherapy in hospitals' OP clinics for PwMS and to further explore the theoretical foundation of neurological physiotherapy.

2. Multiple sclerosis

2.1 Diagnosis and course of the disease

MS was first described by Jean-Martin Charcot in 1868 (Poser & Brinar, 2004), and the aetiology of the disease is still not clear (Compston & Coles, 2008). The prevalence of MS is approximately 2.5 million cases worldwide (WHO, 2001) and approximately 7000 cases in Norway (Torkildsen, Grytten, & Myhr, 2007). The onset of the disease typically occurs between the ages of 20-40 years, with an average age of onset of 30 years; in addition, women are affected 1.5 to 2 times more often than men (Myhr, 2010). The course of the disease is characterised by variation and unpredictability. PwMS can anticipate a near normal life expectancy (reduction of approximately 5-10 years) (EMSP, 2012), which highlights the need for coordinated multidisciplinary health care services at both the primary and speciality health care level.

MS is classified as a chronic immune-mediated inflammatory demyelinating disease affecting the central nervous system (CNS) (Compston & Coles, 2002, 2008). The exact immunological mechanisms in MS are complex and not fully understood (Pugliatti et al., 2008). Symptoms often present as attacks (relapses or exacerbations) lasting a minimum of 24 hours (defined as a relapse) followed by full or partial remission (Polman et al., 2011). In most PwMS (80-90 %), the disease runs in a relapsing-remitting course (RR-MS); the relapses are extremely variable in frequency and severity, and newly developed symptoms can be completely or incompletely resolved (Myhr, 2008). After a varied period, this relapsing-remitting course will proceed to a slowly progressive phase, often without any relapses; this pattern describes secondary progressive MS (SP-RR). A minority of patients (10-20 %) will suffer a primary progressive course (PP-MS) without relapses but with a slow increase of symptoms and disabilities (Compston & Coles, 2008; Myhr, 2008).

The diagnosis is based on a thorough history, including a clinical neurological examination, Magnetic Resonance Imaging (MRI), cerebrospinal fluid tests and a Visual Evoked Response (VER) test. Diagnostic criteria, such as the McDonald Criteria, have been developed (McDonald et al., 2001) and were recently revised (Josey et al., 2012; Polman et al., 2011). In

RR-MS, the diagnosis is based on objective verification of disseminated disease over time (2 attacks or more) and localisation (2 or more lesions in the CNS) with no other explanation of the symptoms. MRI and examination of the cerebrospinal fluid should always be conducted both for the verification of the diagnosis and exclusion of other disease. Primary progressive MS may be more difficult to diagnose but may be established after at least one year of progressive development of symptoms complemented by positive signs from MRI, the VER test and cerebrospinal fluid (Josey et al., 2012).

There is no cure for MS, but medical treatments may slow down the progression of the disease (Compston & Coles, 2008; Myhr, 2010). The medical treatment of the acute attacks (corticosteroid therapy) and treatment of the underlying disease in RR-MS (immune-modulating agents) are monitored closely by a neurologist in accordance with national guidelines (Helsedirektoratet, 2011). The medical treatment may affect the patient's general condition both positively and negatively, which is important to consider when planning individualised physiotherapy.

The neurological impairments and degree of disability are measured using clinical recording systems. The most widely used system is the Expanded Disability Status Scale (EDSS) (Kurtzke, 1983), which is graded from 0 (no signs or symptoms) to 10 (death). An EDSS score of 4.0 is defined as restrictions in walking more than 500 meters, 6.0 indicates a need for a crutch to walk 100 meters, and 7.0 indicates a permanent need for a wheelchair for ambulation (Kurtzke, 1983). In a population of untreated PwMS, 50 % will experience restrictions in walking distance (EDSS=4.0) after 8-10 years, a need for a walking aid to walk 100 meters (EDSS=6.0) after 20 years, and the need for a wheelchair (EDSS=7.0) after 30 years of the disease (Myhr et al., 2001). The huge variety both in clinical symptoms/signs and in the progression of the disease requires that the services, including physiotherapy, should be systematic and flexible to the individual's needs throughout the course of the disease.

In the initial stage, assisting with acceptance of the diagnosis, defining individual needs, and providing information and counselling are key elements in the service (EMSP, 2012; Janssens

et al., 2004). Individualised verbal information, supplied by written information and pictures, is emphasised in addition to educational courses for newly diagnosed PwMS (Borreani et al., 2011; Giordano et al., 2010; Solari et al., 2007; Solari et al., 2010). The need for such tailored information and counselling is emphasised at all stages and, in particular, during the initial phase (EMSP, 2012). However, it is predominantly the verbal information that is highlighted in these reports. The significance of perceptions of one's own movement and bodily experiences related to or integrated into such informational "packages" is an understudied area.

Physiotherapy treatment is advocated when moderate and severe sensory-motor symptoms are present (NICE, 2004). However, we may question whether the decision to wait until moderate movement dysfunctions appear is the optimal approach over time; during this period, neuroplasticity mechanisms may compensate or "cover up" for considerable destructive changes in the brain as described by Pelletier, Audoin, Reuter, and Ranjeva (2009). Neuroplasticity is an essential theoretical basis for neurological physiotherapy and rehabilitation (Raine, 2009; Shumway-Cook & Wollacott, 2012); treatment strategies should be based on specific training to enhance the neuroplasticity mechanisms of the CNS (Pelletier et al., 2009). Thus, it is necessary to briefly discuss some aspects of neurophysiology and plasticity related to MS.

2.2 Aspects of pathophysiology and neuroplasticity

The information flow in the CNS is complex, and axons play a fundamental role. The myelin sheaths around the axons enable efficient and rapid propagation of nerve impulses and provide protection of the axons (Kotter, Stadelmann, & Hartung, 2011). Lesions in MS occur predominantly in the white matter and less frequently in the grey matter (Compston & Coles, 2002, 2008). These active lesions are characterised by a loss of myelin around the axons accompanied by perivascular inflammation involving T-lymphocytes, macrophages and hypertrophic astrocytes. Damage to the blood-brain barrier occurs and a local oedema evolves, followed by inflammation mediated damage of the myelin through various mechanisms (Compston & Coles, 2008). Axonal damage leads to ineffective conduction of impulses. Consequently, a major problem in MS is disturbed information flow within the

neuronal networks in which the damaged sites are involved. However, the inflammation itself promotes re-myelination, a process in which oligodendrocytes and their precursors provide an important function (Kotter et al., 2011). Following a demyelinating incident, oligodendrocyte precursor cells are rapidly amplified in areas of demyelination, which causes remyelination (Kotter et al., 2011). Remyelination is extensive in the early stages of MS and is incomplete in progressive MS (Goldschmidt, Antel, König, Brück, & Kuhlmann, 2009), which indicates the loss of some of the capability to remyelinate as the disease develops. However, even in advanced MS, oligodendrocytes are still present which indicate some potential for regeneration (Kuhlmann et al., 2008). These neural remission processes that occur between the attacks provide, together with general principles of neuroplasticity described by many authors (Brodal, 2010a; Kleim et al., 2002; Nudo, Plautz, & Frost, 2001; Wieloch & Nikolich, 2006), the neurobiological basis for physiotherapy for PwMS.

Neuroplasticity enables parts of the CNS to change form and function as a consequence of internal or external changes (Brodal, 2010a, pp. 147-156; Kleim et al., 2002; Nudo, 2003). An internal change, such as a lesion in the CNS, promotes the immediate release of nerve growth factors, followed by axonal sprouting, cortical re-organisation and establishment of alternative neuronal chains (Fawcett, Rosser, & Dunnet, 2002). The axonal sprouting in early phases of MS is more extensive than for example traumatic head injuries, but less in the chronic phases (Schirmer, Merkler, König, Brück, & Stadelmann, 2012). These neural mechanisms are augmented through active use, such as during movement (Brodal, 2010a; Kleim et al., 2002; Murphy & Corbett, 2009); this use has been termed “user-pressure” by Brodal or activity dependent plasticity. The activation of motor units induces plastic changes in the alpha motor neurons, the innervated muscles and the connective tissue (Dahl, 2008). Hence, the neuromuscular system is adaptable.

Researchers are starting to focus on neuro- and muscle-plasticity related to physiotherapy. Biological mediators, such as neurotropic factors and anti-inflammatory cytokines, may be related to exercise management (Heesen et al., 2006). Recent studies (Dalgas & Stenager, 2012; U. Dalgas et al., 2010) have shown that muscle fibre growth follows strength training, and preliminary results from Ibrahim et al. (2011) indicate immediate and long-term positive

effects of physiotherapy on clinical functions and brain microstructure in PwMS using facilitation techniques. However, all these studies are very preliminary.

A basis for guiding plasticity mechanisms is user-pressure, involving focused attention and motivation, where the latter augments the duration of synaptic changes which are positive for motor learning (Brodal, 2010a, pp. 147-155). These considerations highlight the importance of the inter-subjective process during physiotherapy, in which important topics for the patient should be presented to impose a positive user-pressure on the neuromuscular system. The opposite situation, stated by Kidd, Laws, and Musa (1992) as “if you don’t use it you lose it”, is based on the negative effects of neuroplasticity that may be termed “learned non-use” (Taub, 2004). In acute phases of MS when “attacks” are active, compensatory networks and ways of moving will develop. Because of the lesions, these patterns of movement are appropriate for this stage of the disease, but are usually not optimal for flexibility and balance. Degrees of compensatory movement strategies may be prolonged even after the acute phases and remyelination due to negative user-pressure or learned non-use. Therefore, muscular weakness may be a consequence not only of a reduced central drive caused by the lesions, but also of disuse.

All of these elements underline the need for specificity and timing in physiotherapy for PwMS; in particular, the early phases of MS are interesting because they involve more options for optimising motor function. Principles of neuroplasticity and muscle plasticity suggest that physiotherapy provides a specific user-pressure that may be advantageous for the patient if the therapy is directed to the patient’s underlying impairments and dysfunctions with ADL and if the therapy is meaningful to the patient.

2.3 Symptoms in MS influencing movement

Symptoms in MS vary depending on which sub-systems are affected and on the person’s premorbid conditions. In most patients, the clinical manifestations involve motor, sensory, visual or autonomic systems (Compston & Coles, 2008). As a background for understanding

physiotherapy to these people, common symptoms will be described and related to the CNS and to normal movement.

Disorders of vision are common; optical neuritis is a frequent symptom at onset and may occur at any stage of the disease (Myhr, Nyland, & Bø, 2010). Vision constitutes a particularly important neurobiological basis for balance (Brodal, 2004), and disorders may lead to functional problems in the upright positions, particularly if vestibular and somatosensory systems are also affected and are unable to compensate for the loss.

Disturbed sensibility is a frequent problem in MS, often from the early phases, and is manifested as paraesthesiae, hyperesthesia, numbness, reduced proprioception (Myhr et al., 2010). These dysfunctions will change the representation of the body in the CNS. In addition, these changes will have consequences for the feed-forward and feedback loops of motor control (Brodal, 2004) that may disturb balance and motor performance in ADL. When the somatosensory systems are impaired, vision is often used as a compensatory mechanism (Mulder, 2003). Based on mechanisms for neuroplasticity, such compensatory strategies may reduce the user-pressure on the somatosensory systems and, therefore, maintain the dysfunctions in these systems, even though some remyelination in the lesions has occurred.

Demyelisation in cortical neurons can be observed from the initial stages of the disease and involves inflammation (Lucchinetti et al., 2011) and reduced number of synapses and neurons (Wegner, Esiri, Chance, Palace, & Matthews, 2006) influencing the descending systems and the cortical networks. Lesions in the ventro-medial pathways lead to problems with postural control, balance and motor activities (e.g., walking), while the ventro-lateral systems are related to more distal functions, such as dexterity of the hands (Brodal, 2010a). Problems may be related to pathological low tone, which will compromise the ability to stay up against gravity and to stabilise one part of the body to allow for movement in another part; therefore, both postural control and selective movement are disturbed. On the other hand, pathological high tone in parts of the body is more often present, compromising the flexibility between eccentric and concentric contractions in the muscles. This condition appears as stiffness,

reduced selectivity of movement and reduced adaptability to the environment. Moreover, pathological high tone is often associated with spasticity. This condition is complex and not fully understood and involves several inhibitory and excitatory mechanisms in which the reticular formation and the spinal networks are especially important (Brodal, 2010a, pp. 320-321). Some authors suggest that one should differentiate between different underlying mechanisms when labelling the pathological tone and especially distinguish neuronal mechanisms from muscular adaptations (Brodal, 2010a, pp. 320-321; Pandyan et al., 2005). Clinically, combinations of high and low tone are frequent, as are areas of hypo- and hyper-sensitivity, hyperreflexia and adaptive muscular shortening that causes malalignment. To provide adequate user-pressure on relevant parts of the neuromuscular system, it seems appropriate in physiotherapy to distinguish between different underlying impairments when pathological tone is present and to analyse their impact on functional movement.

Coordination of movement is vital for successful performance of ADL, and the cerebellum is a key area for achieving this. However, the cerebellum is the site of demyelination in 90 % of PwMS in the chronic stage (Kutzelnigg et al., 2007), leading to dys-coordination of movement. Lesions in the cerebellar hemispheres are associated with dysarthria and tremors in the extremities, while affection of the vermis and para-vermis cause postural ataxia, impaired locomotion and reaching and dysfunctions in the floccular node may lead to nystagmus and ataxia in the trunk (Brodal, 2010a). From a clinical point of view, these various forms of dys-coordination often lead to compensatory fixation strategies in global muscles in the feet, hips/pelvis, shoulders, neck and the jaws. These strategies serve to counteract the uncontrolled movements and enable the person to balance and to reach and grasp in ADL, although often in a deviant way. These fixation strategies prioritise the activation of phasic muscles instead of the tonic muscles that normally conduct efficient postural control. As phasic muscles are less enduring (Dahl, 2008), overuse of these may exaggerate fatigue (abnormal exhaustion), which affects up to 80 % of PwMS (Myhr et al., 2010). These considerations underline the importance of addressing the quality of movement in physiotherapy for PwMS. This brief overview, in which cognitive dysfunctions could be added, provides some of the rationale for an individualised approach to physiotherapy.

To summarise, the sensory-motor disturbances in MS cover a huge spectrum and may lead to various motor problems with ADL. However, the same ADL, for example walking, may have a variety of clinical manifestations; depending on the premorbid condition, on which networks are affected and on how the CNS has adapted movement patterns following to the lesions. To direct the user-pressure during treatment to appropriate neuromuscular sites, the need for a systematic and individualised assessment is fundamental. Detailed movement analyses regarding balance, gross-motor function and dexterity related to ADL are recommended in neurological physiotherapy (P. Johnson, 2009). This clinical reasoning process, which is informed by theory and clinical experience, may be strengthened if it is related to systems' control of movement. In functional movement, the sensory, motor, premotor, perceptual, emotional, cognitive and coordinative systems are highly integrated. Thus, the neurobiological background for the initiation of movement, including feed-forward and feedback during movement, should be understood. This network-based understanding of the CNS underlines the importance of relating signs and symptoms of MS to prerequisites for human movement and to the person with MS' experiences and expectations concerning functional activities.

3. Physiotherapy and MS

Physiotherapy is a complex inter-subjective process between the physiotherapist and the patient, in which the physiotherapist integrates theoretical knowledge, clinical experience and skills with relational, ethical and contextual aspects (Dahlgren, Richardson, & Kalman, 2004; Higgs & Jones, 2008; Thornquist, 1998, 2009). The physiotherapist's actions in the particular setting must be adapted to the specific patient and to his/her situation to construct a meaningful situation for the patient. Professional considerations, including assessment and dialectical clinical reasoning based on theoretical knowledge and prior experiences, inform the choice of interventions (Edwards, Jones, Carr, Braunack-Mayer, & Jensen, 2004; M. Smith, Higgs, & Ellis, 2008). Due to the complexity of professional practice, how the interventions are conducted and tailored to the individual may influence what the patient gains from the specific therapy. Keeping the multifaceted characteristics of clinical practice in mind, it is fundamental to be informed of what is known to be effective for PwMS and to be updated on knowledge derived from research on the patients' and the professionals' perspectives.

3.1 Effects of physiotherapy and physical training in PwMS

Although the evidence for the effect of physiotherapy for PwMS is insufficient, there are a growing number of studies indicating positive outcomes of various approaches. A review indicates mixed, but generally positive effects of various physiotherapy interventions (Hogan & Coote, 2009). Therapy based on the Bobath Concept improved gait and balance in PwMS (Smedal et al., 2006) and has also been shown to improve physical performance, health related quality of life (HRQoL), fatigue and ADL, particularly when conducted in warm climate (Smedal et al., 2011). Rasova et al. (2006) compared individualised physiotherapy for PwMS by studying four groups of patients who received the following approaches: 1) hands-on facilitation techniques (neurophysiological-based), 2) aerobic training, 3) a combination of the two interventions and 4) no intervention (control group). Patients in the intervention groups improved; however, the neurophysiological-based intervention had a greater impact on the EDSS, while the aerobic training had a greater effect on the breathing parameters. Wiles et al. (2001) showed that specialised physiotherapy using hands-on facilitation techniques led to improvements in balance, walking, well-being and mood. In a review, Wiles (2008) reported

benefits from rehabilitation approaches, including physiotherapy; however, none of the studied approaches was superior to others.

A recent systematic review indicated a small but significant effect of various physiotherapy interventions on balance in PwMS who have a mild to moderate degree of disability (Paltamaa, Sjögren, Peurala, & Heinonen, 2012). A pilot study (Freeman et al., 2010) described the effects on gait and balance in ambulant PwMS after an eight week physiotherapy program that focused on individualised core stability training using a Pilates approach; this study is now followed up by a larger RCT study (Freeman, Fox, Gear, & Hough, 2012). The results from this study will be interesting, because core stability according to for example Kibler, Press, and Sciascia (2006) is vital for balance, selective movement and strength in the extremities.

Furthermore, interventions comprising group circuit strengthening, balance classes and individualised treatment were found to significantly improve motor functions, fatigue and HRQoL in PwMS (Garrett et al., 2012; Vikman, Fielding, Lindmark, & Fredrikson, 2008). Individualised physical therapy in combination with follow-up phone-calls has been reported to have more physical benefit for PwMS than a similar group-based intervention (Plow, Mathiowetz, & Lowe, 2009). To summarise, positive effects regarding gait, balance, ADL, fatigue and HRQoL have been demonstrated for physiotherapy alone or included in a multidisciplinary program, and individualisation seems to produce greater benefits.

In recent years, strength training and fitness training have been considered beneficial therapies for PwMS, as opposed to the previous view that exercise may worsen symptoms due to a rise in body temperature. Increase in sensory symptoms following a single session of strength and fitness training is demonstrated, by R. M. Smith, Adeney-Steel, Fulcher, and Longley (2006), but these were temporary and without a change in activity or fatigue. Several studies have suggested that strength training for PwMS has positive effects; for example on HRQoL, fatigue and mood (Andreasen et al., 2011; U. Dalgas et al., 2010), on kinematics in gait (Gutierrez et al., 2005); aerobic capacity (Dalgas et al., 2009; J. Hoff, Gran, & Helgerud, 2002). Most studies have used a low- to moderate-intensity intervention (Broekmans et al.,

2011; Dalgas et al., 2009; De Souza-Teixeira et al., 2009). A recent systematic review reported strong evidence for effect of strength training on mobility and muscle function, uncertainty as concerns effect on fatigue and no program is in favour of others (Rietberg et al., 2011).

Overall, reports support individually adapted strength and fitness training, emphasise quantitative measures but provide less detailed information on how the activities are performed. A recent small study based on non-participating observation of strength training for PwMS (EDSS 3.0 and 4.0) reported a risk of strengthening already established non-optimal compensatory strategies, unless specific tailoring and hands-on techniques were used (T. Hoff, 2012). The performance of training may, based on neuro- and muscle-plasticity, influence what will be improved or learned as described by Levin, Kleim, and Wolf (2009) with regard to rehabilitation following stroke. Research data focusing on how to enable a person to perform exercises in an optimal way, both under guidance and on their own, are limited. Exclusively verbal instructions may have limitations for addressing the altered neural, muscular and biomechanical prerequisites for movement in PwMS, as words require cortical-driven motor control and assume that the mentioned prerequisites for movement are intact.

The reviewed literature is ambiguous and presents a variety of therapeutic approaches, intensity, measurements and clinical settings, and is suggesting effects on various aspects of ADL. There is no indication of one specific approach being more preferable. Individualisation is emphasised as a therapeutic principle. Research focusing on the investigation of individualisation in authentic clinical practice and includes patients' perspectives is sparse.

3.2 The user perspective in physiotherapy to PwMS

An understanding of the user perspective is important for the development of health care services (Helse- og omsorgstjenesteloven, 2011). Studies of PwMS's experiences with physiotherapy are limited. Dodd et al. (2006) reported positive evaluations from group strengthening training; the analysis focused on group dynamics rather than content. A need for individualisation concerning the timing of referral and the content of in-patient

rehabilitation is suggested (Andreassen & Wyller, 2005), and physiotherapy in out-patient settings, and optional access to multidisciplinary hospital services during a relapse is positively evaluated (Dawson, Jones, Lhussier, & Buri, 2004). Other authors document the importance of strategies that enhance perceived control over fatigue and promote self-caring (C. Smith, Hale, Olson, & Schneiders, 2009). Moreover, subjective quality of life is influenced by the patients' degree of disability and their coping capacity (K. Gottberg et al., 2006); a need for learning coping strategies in the initial and early phases of MS has been reported (Lode et al., 2010; Lode et al., 2007). However, these reports mainly present coping strategies and information as cognitive processes, where movement has no role or only plays an implicit role. A pilot study by Plow et al. (2009) suggested integrating physical activity with coping strategies. The reviewed literature indicates a need to explore experiences following single sessions of physiotherapy in OP clinics for PwMS and, in particular, experiences involving body and perceptions of movement.

Patient satisfaction constitutes an element of the user perspective and is recognised as essential in the evaluation and development of health care (Fitzpatrick, 2002 ; Helse- og omsorgstjenesteloven, 2011). Patient satisfaction is a complex construct in which elements such as expectations, interpersonal relationships, psychological factors and the effect of intervention may influence the user's opinions of a service (Sitzia & Wood, 1997). Studies of user satisfaction are often criticised for showing high and undifferentiated levels of satisfaction (Fitzpatrick, 2002 ; Lian & Wilsgaard, 2005; Sitzia, 1999; Sitzia & Wood, 1998). Sitzia and Wood (1997) suggested that an important divide exists between highly satisfied patients and those who report more moderate satisfaction levels (i.e. those who simply indicate that the service was not extremely poor). Hills and Kitchen (2007 a, b) proposed that patient satisfaction in physiotherapy depends on bio-psycho-social needs being met as much as the success of the therapeutic intervention. From the user perspective, self-perceived short- and long-term changes in movement following physiotherapy are considered as outcomes of care.

The research on patient satisfaction in physiotherapy is limited compared to other health disciplines (Hills & Kitchen, 2007a). Studies including patients with a variety of diagnoses in community outpatient settings (Casserley-Feeney, Duffy, Roush, & Hurley, 2006; O'Sullivan,

Gilchrist, Holland, & Langford, 2006); and in rehabilitation centres (Stiller, Cains, & Drury, 2009) have reported a high degree of satisfaction with the overall standard of the physiotherapy service and with therapists' interpersonal skills. In an older study, Roush (1995) reported a high satisfaction from PwMS regarding interpersonal factors but less satisfaction with the physiotherapists' technical skills in the primary healthcare setting. In a pilot survey performed in a British hospital, Gillanders et al. (2006) described a high degree of satisfaction with physiotherapy among PwMS but also noted a lack of teaching and guidance in self-assisted training. High patient satisfaction with multidisciplinary services, including physiotherapy, has been reported from a four-week in-patient rehabilitation program for PwMS in Norway (Holmøy, Hanssen, & Beiske, 2012). To summarise, a high satisfaction with physiotherapy has been reported for PwMS, and these findings are similar to results from other fields. The methodological weaknesses of these studies are that the samples were small, a variety of mostly non-validated questionnaires were used, and only a few studies examined physiotherapy for PwMS. Studies that explore the experience of PwMS regarding physiotherapy in the hospitals' outpatient clinics were not found.

3.3 Competency in neurological physiotherapy

Professional competency is a vital component of quality health care, and the availability of adequate expertise in the community and in the speciality health care field is a prerequisite for continuity of care. In Norway, there are currently 67 authorised specialists in neurological physiotherapy practicing in 16 of the 19 counties in the country (NFF, 2012a). Only eight specialists work in the communities, while the majority are employed in specialised health care settings (NFF, 2012a). The need for more expertise in this field at the municipality level is obvious, and the government has requested and financially initiated the development of programs to promote competency in neurological rehabilitation (HOD, 2011). In addition, the Norwegian physiotherapy association has promoted CPD for physiotherapists (NFF, 2012b). Professional guidance during clinical sessions is one of many learning activities suggested to promote CPD in physiotherapy (Fleet et al., 2008; French & Dowds, 2008). Guidance and supervision of professionals are the responsibilities of specialised health care (Helse- og omsorgstjenesteloven, 2011). A key element for improving patient care is the implementation of learning through reflective practice, which involves discussions with colleagues regarding treatment approaches (Dowds & French, 2008; Wainwright, Shepard, Harman, & Stephens,

2010). Mentorship from an expert facilitates the development of expertise in physiotherapy (Petty, Scholes, & Ellis, 2011; Wainwright et al., 2010). Clinical sessions, demonstrations of patient management and discussions facilitate learning in physiotherapy students (Ernstzen, Bitzer, & Grimmer-Somers, 2009). However, the use of clinical guidance in OP clinics for PwMS to enhance professional development of authorised cPTs has not gained much attention in research.

A review of the literature reveals a lack of knowledge concerning physiotherapy in OP clinics for PwMS and, in particular, a lack of insights derived from PwMS's and cPTs' perspectives. The biomedical perspective as a framework for research dominates and may restrict the conceptualisation of central elements of physiotherapy. Body and movement are conceived as fundamental areas of focus in physiotherapy when assessing, treating, and guiding the patients. Several authors have suggested that conceptualisation of these vital elements in physiotherapy will enhance professional development (Broberg et al., 2003; De Souza, 1998; B. E. Gibson et al., 2010; Nicholls, 2012; Nicholls & Gibson, 2010 ; Nicholls & Holmes, 2012; Wikström-Grotell & Eriksson, 2012). These recent studies provide post-structural theories as a framework to understand physiotherapy; however, a perspective based on the phenomenology of the body has been absent as a theoretical position in this context. Kay S. Toombs (1995) used this framework to analyse her own experience from living with MS. In physiotherapy, this perspective has been used to gain a deeper understanding of people with psychomotor problems (Eckerholdt & Bergland, 2006) and physiotherapy for children (Øberg, 2008). So far, phenomenology of the body has not been widely used as a theoretical concept for neurological physiotherapy nor, in particular, in the context of physiotherapy for PwMS. This theoretical position will be elaborated in the following sections.

4. Theoretical framework of body, movement and knowledge

Philosophical traditions may serve as a theoretical framework to gain a deeper understanding of clinical practice and of the theoretical foundation of physiotherapy. Phenomenology is one of these epistemological traditions in which several directions have been developed. In the subsequent section, particularly relevant aspects of phenomenology from the French philosopher Maurice Merleau-Ponty's theory of the embodied self (Merleau-Ponty, [1962] 2008) will be presented, followed by the philosopher Shaun Gallagher's (2005; Gallagher & Zahavi, 2008) conceptions of body image and scheme, sense of ownership and agency; theories in which neurosciences of relevance for motor control will be explicitly integrated. Phenomenology of the body is of particular relevance because PwMS have lesions in the CNS (described in section 2) that directly influence the embodied self as described by the mentioned philosophers. The theory of embodiment will be used for analysis of the qualitative material in the current study. Furthermore, a theory of practice knowledge will be presented and will be used in the analyses of the cPTs' reflections following professional clinical guidance in the current study.

4.1 The phenomenology of the body

Merleau-Ponty (1908-1961) based his work on Husserl's and Heidegger's theories and was the first to give epistemological priority to the body by giving the body a first-person status. For the purpose of the current thesis, Merleau-Ponty's theory was convenient because it emphasises the ambiguousness of the body, suggesting the body is the centre of experience and expression at the same time as it is a biological and biomechanical organism. With this perspective, lesions in MS can never be considered in isolation from the experiencing and expressing body. The experiencing and expressing body is, for the phenomenologist, the *body-as-subject*.

4.1.1 The ambiguousness of the body

According to Merleau-Ponty, being a body has a primacy, as this is our ordinary way of *being-in-the-world* or "*être-au-monde*", to use his original term (Merleau-Ponty, [1962] 2008, p. 94). Hence, it is through *being* a body that we realise that we *have* a body and become conscious of the world and the physical objects around us. However, although the

body is a visible biological organism and a biomechanical system that may be referred to in third-person terms, the body is never equivalent with other physical objects in the world because of the simultaneous first-person status of the body (Merleau-Ponty, [1962] 2008, pp. 84-94). As bodies, we can touch and see simultaneously as we are touched and seen (Merleau-Ponty, [1962] 2008). This characteristic implies that touch in physiotherapy is a part of the interaction between two embodied subjects. In this framework, physical interaction and handling in physiotherapy could be termed as a part of communication, which implies that more than words and gestures constitute the elements from which meaning is constructed in the clinical setting.

The ambiguousness of simultaneously being and having a body is usually not a matter for our consciousness because our *own body (le corps propre)* is normally not in our perceptual field, but rises towards the world accompanied by a pre-reflective awareness (Merleau-Ponty, [1962] 2008). The philosopher and medical doctor Drew Leder (1990), who draws on Merleau-Ponty's work, uses the term *dis-appearance* to describe this normal situation, while *dys-appearance* refers to a situation when one's own body comes explicitly in focus with one's attention, as often is the case in disease. Such a displacement or alteration within the relationship between the body-as-subject and the body-as-object is a relevant framework to understand PwMS because movement and sensory disturbances may influence capacities to engage with the world. Based on experience with MS, Toombs (1995) proposed that loss of mobility includes a change in the character of the surrounding space, an alteration in one's taken-for-granted awareness of (and interaction with) objects, the disruption of corporeal identity, a disturbance in one's relations with others, and a change in the character of temporal experience. The loss of upright posture is of particular significance because this loss not only concretely diminishes autonomy, but also affects the way one is treated by others. Such a change in posture is, according to Toombs, particularly disruptive in the social world of everyday life. These considerations allow for an extension in terms of how physiotherapists may understand balance problems in PwMS.

4.1.2 Intentionality

According to Merleau-Ponty ([1962] 2008), the body and its surroundings constitute an inner relationship or a *to-from* structure in which both “elements” are interdependent, a notion that is emphasised by the hyphen between the words in *being-in-the-world*. This statement indicates that the relationship between the body and the world is fundamental. Being-in-the-world involves a pre-objective view of the world brought forward by the entity’s motility, sensation and perception, which in Merleau-Ponty’s theory constitutes embodied intentionality. His words: “Consciousness is not about ‘I think that’, but of ‘I can’” (Merleau-Ponty, [1962] 2008, p. 159), which highlights the primacy of motility in intentionality. Across the Cartesian divide, movement prefigures the lines of intentionality, gesture formulates the contours of social cognition, and, in both the most general and most specific ways, embodiment shapes the mind (Gallagher, 2005, p. 1). Considering the elements of intentionality as an entity from which meaning evolves for the embodied self implies that these elements should not be seen as separated from each other. However, the specific sensory modalities, touch, pain, proprioceptive sense, vision and auditory sense, and their corresponding sense organs, ascending pathways in the CNS, multisensory networks and descending motor pathways and networks, are fundamental body structures and functions underpinning embodied intentionality. In PwMS, all of these systems are potential sites for lesions and hence influence the person’s actual way of being-in-the-world. However, in Merleau-Ponty’s theory, these components could never be reduced to just neurophysiological structures and functions extracted from the body as a subject (Merleau-Ponty, [1962] 2008, p. 159). In physiotherapy, this understanding may bring consequences for how neurological assessment is contextualised.

The to-from dimension in intentionality implies both a pre-reflective and a reflective level in which the body is the centre of experiences and contributes to the constitution of the perception and the meaning of physical objects (Merleau-Ponty, [1962] 2008). Physiotherapy for PwMS may involve addressing both pre-reflective and reflective aspects of intentionality. The pre-reflective level has its biological correlate in subcortical processing of sensory-motor systems described in neurobiology. This level disengages the cortical networks from dealing with how to move and allows attention to be directed outwards towards the opportunities and affordances of the surroundings. This notion implies that meaning evolves from the particular

contexts of being-in-the-world. This pre-reflective embodied intentionality or the *intentional arch* may be weakened in pathological states (Merleau-Ponty, [1962] 2008); therefore, MS may lead to a weakened intentional arch and an alteration in their engagement in ADL similar to what Toombs (1995) described.

4.1.3 The habitual and the present body

Merleau-Ponty describes two “layers” of the body: the *habitual body* where all former experiences are incorporated and serve as the basis for how the *present body* engages in the situation. Furthermore, what the present body does now will be incorporated into the future habitual body (Merleau-Ponty, [1962] 2008). Lesions due to MS will influence which former movement experiences are available for the person and hence direct his/her engagement in the present situation. Furthermore, it is appropriate to draw the connection to neuro- and muscle-plasticity previously described (Section 2.2, 2.3) as the biological correlate to incorporation of experiences like movement. These biological effects are strongest if the person in question experiences the situation as meaningful (Brodal, 2010b); therefore, the inter-subjective process between the physiotherapist and the patient, in which physical interactions is integrated, may enhance or inhibit the patient’s construction of meaning. Furthermore, the body as the centre for experience, termed as the *lived body*, involves both the habitual and the present body and implies both a pre-reflective and a reflective level (Merleau-Ponty, [1962] 2008). In other words, experiences all the way throughout life are incorporated. Hence, PwMS are lived bodies in which experiences both prior to and after diagnosis are incorporated, and movement and other experiences during physiotherapy will be cemented in the body.

4.1.4 Proprioception

Proprioception is an aspect of posture and movement that may deepen the comprehension of the embodied self, and may act as a starting point to derive new knowledge from PwMS’s experiences with physiotherapy. Proprioception (including kinaesthesia) is a key element in human movement and may be defined in slightly different terms in various disciplines. According to Gallagher (2005, p. 7), proprioception can mean non-conscious information in a neuroscience context or it can mean a form of conscious awareness in a psychology context.

These two aspects of proprioception are fully integrated at the embodied experiential level. Furthermore, the psychologist James Gibson enlarged the definition and described proprioception as the integration of all modalities of sensory information concerning one's own body as a moving agent in the environment with the intra-corporeal information provided by an internally generated sense of posture and movement (Gallagher, 2005, pp. 7, referring to Trevarthen 1986 and Gibson 1979). Gallagher's elaborations of proprioception form a vital element in the concept of embodiment that is highlighted in the following statement:

“Bodily movement is closely tied to various forms of perception and to other forms of cognitions and emotion. Indeed, there is now a large amount of evidence from a variety of studies and disciplines to show that the body, through its motor abilities, its actual movements, and its posture, informs and shapes cognition”. (Gallagher, 2005, p. 8).

Therefore, the interlinking of pre-reflective experiences of proprioception through posture and movement (that is, implicit posture and movement generated in part on a subcortical level) with reflective activities, such as verbal dialogue, appears to serve as a concept suitable for exploring authentic physiotherapy practice characterised by a combination of physical interaction and verbal dialogue. Other terms that underpin this concept are discussed in the following sections.

4.1.5 Body schema and body image

Body schema and *body image* are important terms related to the first-person perspective that have been used inconsistently in multiple disciplines² (as noted by Gallagher, 2005) . According to Gallagher (2005), these terms refer to different, but closely related, systems that are integrated in the performance of ADL. A body image consists of a system of perceptions, attitudes, and beliefs that is pertaining one's own body, and a body schema or multiple body schemas are systems of sensory-motor capacities that function without awareness or the necessity of conscious perceptual monitoring (Gallagher, 2005, p. 24). Body schema is a deepening of the sensory and perceptual aspects of Merleau-Ponty's term 'intentionality', including the ascending systems with the integration at the spinal, brainstem, midbrain,

² Merleau-Ponty used the term *schema corporel*, which has been mis-translated into English as “body image” (Gallagher, 2005, p. 20).

cerebellar, and cortical levels to accomplish being-in-the-world or being engaged in the world. Disruptions in the CNS (caused by lesions) may motivate conscious perception and monitoring of movement because we are capable of changing our perspective (figure/ground); therefore, movement in pathological conditions, such as in PwMS, may be more body image driven. In the literature, unilateral neglect following stroke is described as an example of a body image problem (Gallagher, 2005, referring to Denny Brown et al., 1952). De-afferentation, as in the case of Ian Waterman who lost his proprioception and touch from the neck down, is an extreme example of a body schema dysfunction (Gallagher & Cole, 1995). The distinctions between body image and schema are relevant for clinical reasoning in neurological physiotherapy for PwMS as these patients may have lesions affecting either or both of these components. Sensory, motor and coordination dysfunctions, which could be classified as body schema dysfunctions, are the most commonly occurring dysfunctions in PwMS. Body schema dysfunctions may lead to more body image driven movement similar to Leder's descriptions of dys-appearance; in the cases where automatic processes of the body schema fail, instead of consciously focusing on the world, the subject reflectively focuses on bodily movement and attempts to control it using the conscious body image. Improvement of body schema functions, for example due to physiotherapy, may lead the body back to the more normal recessed or pre-reflective awareness, or the dis-appearance that allows the person to be attentive to the world on the basis of body schema driven movement. As physiotherapy for PwMS aims to improve ADL and the ability to participate socially, a quest for body schema driven movement could be optimal, while body image driven movement could be more associated with compensatory strategies. The assessment and exploration of options for change in prerequisites for movement may reveal whether more body schema driven movement is possible.

4.1.6 Sense of ownership and sense of agency

Body schema and body image form the basis for the *sense of ownership* (SO) and *sense of agency* (SA), which are integrated concepts described by Gallagher (Gallagher, 2005; Gallagher & Zahavi, 2008). Gallagher describes SO as a type of minimal self (-experience), which includes pre-reflective, proprioceptive and ecological experiences connected with sensory-motor processes. SO is the experience or sense that “my body is moving or is still” and “I am the subject or the owner of my movement” (Gallagher, 2005, pp. 25-39). SO

implies a strong afferent component, such as the involvement of spino-cerebellar, spino-thalamic and lemniscus medialis systems, with integration networks in the spinal cord, reticular formation, cerebellum, cortex and, in particular, the parietal lobe. The afferent systems are often disturbed in PwMS, which may have an impact on the SO of these people.

SA implies a pre-reflective experience or the sense that “as I act, I am the cause/initiator of my action and have some control over it” (Gallagher & Zahavi, 2008 p. 161). This sense depends on the pre-action motor control processes in the cortex (e.g., the supplementary premotor cortex), efferent networks that generate pre-action dynamic stability (e.g. the reticulo-spinal, and the vestibulo-spinal systems in conjunction with cerebellum and the basal ganglia), often termed Preparatory Anticipatory Adjustments (APAs) in physiotherapy (Meadows & Williams, 2009; Shumway-Cook & Wollacott, 2012). As described, PwMS often have impairments in their executive and/or coordinative networks which may lead to a changed or reduced SA. Being the initiator of one’s own movement and controlling the performance appear to be closely related to autonomy, and may therefore involve engagement in everyday life. Physiotherapy may aim not only to improve strength, endurance and range of movement, but also aim to strengthen the SA.

During ADL, the SA and SO are indistinguishable; this relationship correlates with the close interactions in the sensory motor networks in the CNS. It is interesting to relate these terms to physiotherapy and, in particular, to active versus passive movements. Passive movement, based on these terms, will not involve the patient as the agent of the movements (leading to a diminished SA), but it may include a SO for the movements if the afferent and perceptual systems are working adequately. Hands-on facilitation techniques in physiotherapy, which involve helping the patient to initiate movement through a partly active component, may involve both the SO and SA. Gallagher’s terms, SO and SA, may open the possibility of a deeper understanding of the disturbances in sensory-motor networks in PwMS and inform interventions in physiotherapy.

Central phenomenological and neurobiological aspects regarding body and movement related

to neurological physiotherapy for PwMS have now been presented. In the next section, practice knowledge as a framework for deepening our insights into cPTs' experiences from professional clinical guidance in an OP clinic for PwMS will be discussed.

4.2 Knowledge and practice

Professional clinical practice should be based on knowledge, and for the last two decades, the demand for evidence-based practice has been growing among physiotherapy professionals and the authorities. Evidence-based practice is informed by relevant, high quality clinical research, patients' preferences and the physiotherapist's practice knowledge, taking into account the contextual factors (Herbert, Jamtvedt, Mead, & Hagen, 2005, pp. 2-5). There is a general agreement on the elements in this definition, but substantial criticism exists regarding the hierarchy within the model, with priority being given to clinical decision making over knowledge derived from meta-analyses of RCT studies (Ekeland, 1999, 2009; Ekeli, 2002) (Dahlgren et al., 2004; Grimen, 2008). The philosopher Harald Grimen (2008) emphasised that knowledge has many facets or integrated forms. According to his descriptions, knowledge has to be expressible (either verbally or through actions), open to criticism, cumulative and transferrable to others. Dependent on the various forms of knowledge, different arenas for transference and development are required (Grimen, 2008). This theoretical position is relevant for analysing professional clinical guidance in physiotherapy that occurs in natural clinical settings.

4.2.1 Knowing-in-action

Physiotherapy is a profession in the interplay between practice and theory. It is what the physiotherapist does in interaction with the patient that enables the patient to improve, maintain or to cope. Practice knowledge, as a part of the above mentioned model, is anchored in both intellectual and incorporated knowledge, as described by the philosophers Donald Schön (1991, pp. 49-51), Grimen (2008, pp. 71-85), and Molander (1996). These philosophers draw on the philosopher Michael Polanyi (1966) who emphasised that "we can know more than we can tell"; this statement refers to the tacit elements in practice knowledge. This concept also relates directly to the phenomenological concept of pre-reflective know-how and what Merleau-Ponty calls the *I can*, which is based on proper body schematic functioning.

These are concepts that apply equally to the patient who needs to cope with practical challenges in the world and to the therapist who has to cope with practical challenges in the clinic.

According to Grimen (2008), aspects of practice knowledge that are difficult to verbalise include the following: 1) identification of various sense qualities through touch, which is relevant for the development of palpation skills in physiotherapy; 2) the immediate recognition entities of movements (gestalts), which are of relevance to movement analyses and 3) the choreography of movements, which is relevant for handling and facilitation skills. Grimen's insights informed the current study, where palpation of the skin and musculature, observation and analysis of ADL movements and the facilitation of movement are dominating features. Furthermore, Schön (1991, pp. 49-54) says that our knowing is *in* our actions and that *knowing-in-action* involves actions, recognitions and judgements that we know how to carry out spontaneously without thinking. This statement is fully consistent with the concept of embodied pre-reflective knowledge and with Merleau-Ponty's terms of habitual and present body.

4.2.2 Active elements in practice knowledge

Schön (1991, pp. 39-40) challenged the concept of technical rationality that originates in positivism and is a process of problem solving through the selection from available means best suited to reach established ends. He criticised this model's inability to capture the complexity, instability, uncertainty, uniqueness, and value-conflict characteristics of practice. In real life, the problems do not present themselves as *given*; rather, the problems must be identified, and endpoints must be determined (Schön, 1991). In physiotherapy for PwMS, the diagnosis provides little information concerning the specific problems facing the patients and what to do in treatment; problem setting will emerge through the inter-subjective process of assessment.

As a reaction to technical rationality's inadequacy to serve as an epistemology for practice, Schön (1991) introduced his practical rationality, in which *reflection-in-action* is a central

term. He argues for the practitioner's need to *read* the unique situation, which indicates that the situation is complex and open for various interpretations. These situations require the identification of the problem or *problem setting*. According to Schön (1991, p. 40), this is a process in which, interactively, the practitioner *names* the things to which he/she will attend and *frames* the context in which he/she will attend to them. In this thesis, clinical practice in physiotherapy is considered to involve complex situations that will be analysed using these terms.

Naming and framing are on-going interactive processes that include re-naming and re-framing as the problem solving proceeds as an integral part of reflection-in-action. This approach highlights the dynamic aspects of practice knowledge. According to Schön (1991), reflection-in-action is a type of "reflection" that is described as a bodily attention towards the interaction in the situation, such as a feel for the music while improvising or a feel for the ball for a baseball pitcher. In the present thesis, reflection-in-action is related to the oPTs' handling and facilitation skills and professional guidance of the cPTs. Schön (1991) and Molander (1996) describes the dynamic process in practice knowledge as *attention-in-action (uppmärksamhet-i-handling)*. Prior experiences serve as a repertoire of knowledge that develops or evolves through attentive or reflective practice (Schön, 1991). The cPTs serve a large variety of patients in the municipalities. Some may therefore have a very small reservoir of experience in the treatment of PwMS, which presents a challenge regarding how to transfer or develop handling skills in professional guidance from an expert physiotherapist.

Schön (1991, p. 54) suggests that surprises play an important role in reflection-in-action. When the expected result of an action does not occur or when it succeeds more than expected, reflection-in-action is facilitated. Often, the practitioner tests a hypothesis, and the results facilitate new actions; reflection-in-action is seen as complementary to knowing-in-action and emphasises the active elements in practice knowledge also described by Molander (1996, pp. 131-162). While reflection-in-action is dependent on embodied attention or awareness (pre-reflective embodied knowledge), reflection-on-action is the conscious reflection afterwards, which to a greater extent implies verbalisation of knowledge. Therefore, the mutual interaction between these processes may develop practice knowledge in physiotherapy.

Practice knowledge is acquired through a first-person perspective; it is experiential, context-bound, contains both verbal and tacit elements and can be developed through interaction with others (i.e., through inter-subjective interactions)(Grimen, 2008). According to Grimen (2008), these characteristics require other forms of communication in addition to words, which can only be acquired and transferred in situations that are open for a first-person perspective. All of these elements enhance professional competency in physiotherapy (Dahlgren et al., 2004) and constitute a theoretical perspective from which clinical guidance in OP clinics for PwMS will be explored.

5. Aims of the study

The overall aim of this study was to derive new knowledge from PwMS's and cPTs' experiences with physiotherapy and clinical guidance in an OP clinic for PwMS to provide a scientific basis for physiotherapy in these settings, and to explore and broaden the theoretical framework for neurological physiotherapy. Focus was directed to what single sessions may imply for the patients concerning the process of care and the potential short-term outcomes, to investigate the role of perceptions of movement as an integrated part of these sessions and to explore what cPTs experienced as vital in professional clinical guidance.

The thesis consists of three parts with the following specific aims:

1. To investigate PwMS's satisfaction with single physiotherapy consultations in a hospital's OP clinic regarding the process and outcomes of care, the latter by focusing on the perception of change in functional activities following single consultations (Paper I).
2. To explore the significance of body and movement during single physiotherapy consultations in a hospital's OP clinic, and to investigate what perceptions of movement may mean for PwMS' insights into their movement disturbances (Paper II).
3. To identify what aspects the cPTs perceive as being significant in professional clinical guidance and how cPTs consider that such guidance may affect their subsequent treatment of PwMS and development of their clinical skills (Paper III).

6. Methodology, materials and methods

In this section, the context of the study first will be described. Then, methodological considerations and reflections regarding choices taken in all parts of the study will be provided.

6.1 Context of the study

The study was performed at the outpatient clinic for PwMS in Nordland Hospital Trust, Norway, from 2006-2007. The hospital serves a population of approximately 240 000 inhabitants. The team in the clinic consisted of neurologists, a nurse with specialist training in MS and a physiotherapist specialised in neurological diseases (an expert). The physiotherapy service in the clinic was new when the study was performed, and the consultations were usually coordinated with the other team members, indicating that the patient normally would visit all three professionals during the same day.

6.1.1 The physiotherapy service at the out-patient clinic

The single consultations lasted 60-90 minutes and were based on the following principles as described in the guidelines for the particular OP clinic:

- Assessment, exploration of treatment and practical guidance emphasising a systematic approach; communication; emotional support; and movement analyses and evaluations.
 - Standardised tests for walking and balance.
 - Analysis of functional activities (sitting and standing balance, reach and grasp, movement from one postural set to another, walking) through a combination of observation, dialogue and handling to identify movement resources and deviations from normal movement.
 - Explorative treatment using hands-on techniques to identify the person's potential options for improving the identified deviations from optimal movement. Re-evaluation of movement performance following the explorative treatment.

- Guidance in individually tailored self-assisted exercises aiming to maintain or improve quality of movement related to ADL.

6.1.2 Professional clinical guidance

After the single sessions, a written report was communicated to the cPTs who were treating or planning to treat the patient in the community, and clinical guidance was offered as an optional follow-up. The professional guidance involved a clinical setting in which the patient (second consultation), the cPT and the oPT were present and was based on the following guidelines at the clinic:

- Observation of systematic assessment and individualised explorative treatment of the patient following the same principles as the above described consultation between the patient and the oPT.
- Discussion of clinical reasoning and subsequent treatment between the oPT and the cPT after the patient had left.

6.2 Study design and methodology

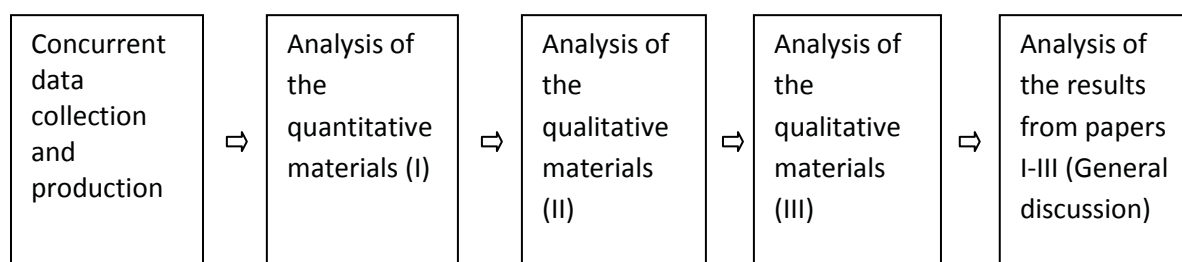
A cross sectional study design (Polit & Beck, 2012) was chosen to gain insight into the user's experiences immediately following the physiotherapy consultations in the OP clinic for PwMS. Based on the overall purpose of the study and the lack of research in this field, a triangulation design (Blaikie, 2010; Polit & Beck, 2012) was applied using both quantitative and qualitative methods. Triangulation of methods is recommended in physiotherapy to bring forward nuanced knowledge relevant for practice (Shaw, Connelly, & Zecevic, 2010). The quantitative approach involved a questionnaire complemented by self-reporting measurements, and the qualitative approach included in-depth interviews and non-participating observations. The use of different methods was targeted to produce nuanced knowledge from all PwMS that participated in the study and more explorative information from individuals following physiotherapy and clinical guidance consultations at the clinic. However, only the patient perspective was addressed by both quantitative and qualitative methods. The present study did not include quantitative data from all of the cPTs who participated in clinical guidance during that period of time, which could be considered a

weakness of the study. On the other hand, prioritising the investigation of the patient's perspective is in line with the authorities' and guidelines' emphasis on the patients' perspectives (EMSP, 2012; Helse- og omsorgstjenesteloven, 2011). Furthermore, to our knowledge, there are no validated and reliable questionnaires available that could record the cPTs' experiences.

We wanted the participants in the study to have recent memory of the experiences in question, and we aimed to produce valid and trustworthy data; therefore, we chose to collect data for the quantitative study (study I) concurrently with the data for the qualitative studies (study II and III). The time limit for the study was seven months, which was too short to collect the data in sequence (quantitative before qualitative or vice versa). An advantage of concurrent data collection was a *nesting* procedure in sampling (Polit & Beck, 2012), which imply that some participants from the large study (Paper I) were also participants in the other investigations (Papers II and III). Hence, both data sets were derived from experiences based on the same consultations, which strengthen the validity of the study.

To use quantitative and qualitative methods concurrently requires particular care because these methods are rooted in different ontology and epistemology (Blaikie, 2010, pp. 225-226; R. B. Johnson & Onwuegbuzie, 2004; Shaw et al., 2010). In the current study, this issue was addressed by using a sequential procedure in the analysis of the material (quantitative before qualitative); this approach has been associated with an explanatory design that allows for one of the methods to be prioritised (Blaikie, 2010, pp. 224-225; Polit & Beck, 2012, pp. 608-613). The results from the quantitative material (Paper I) were analysed first, and then the qualitative materials focusing on the PwMS (Paper II) and the cPTs (Paper III) were analysed consecutively. Finally, the results from the three papers were analysed together, and these results are presented in the General discussion. The qualitative methods are given priority in the current discussion because two of the studies (II and III) were based on these methods; furthermore, the lack of research in the field and the aim to further explore the theoretical foundation for neurological physiotherapy suggested that a focus on these methods was appropriate. An overview of the sequences in the study is presented below in Figure 1.

Figure 1. An overview of the sequences in the study



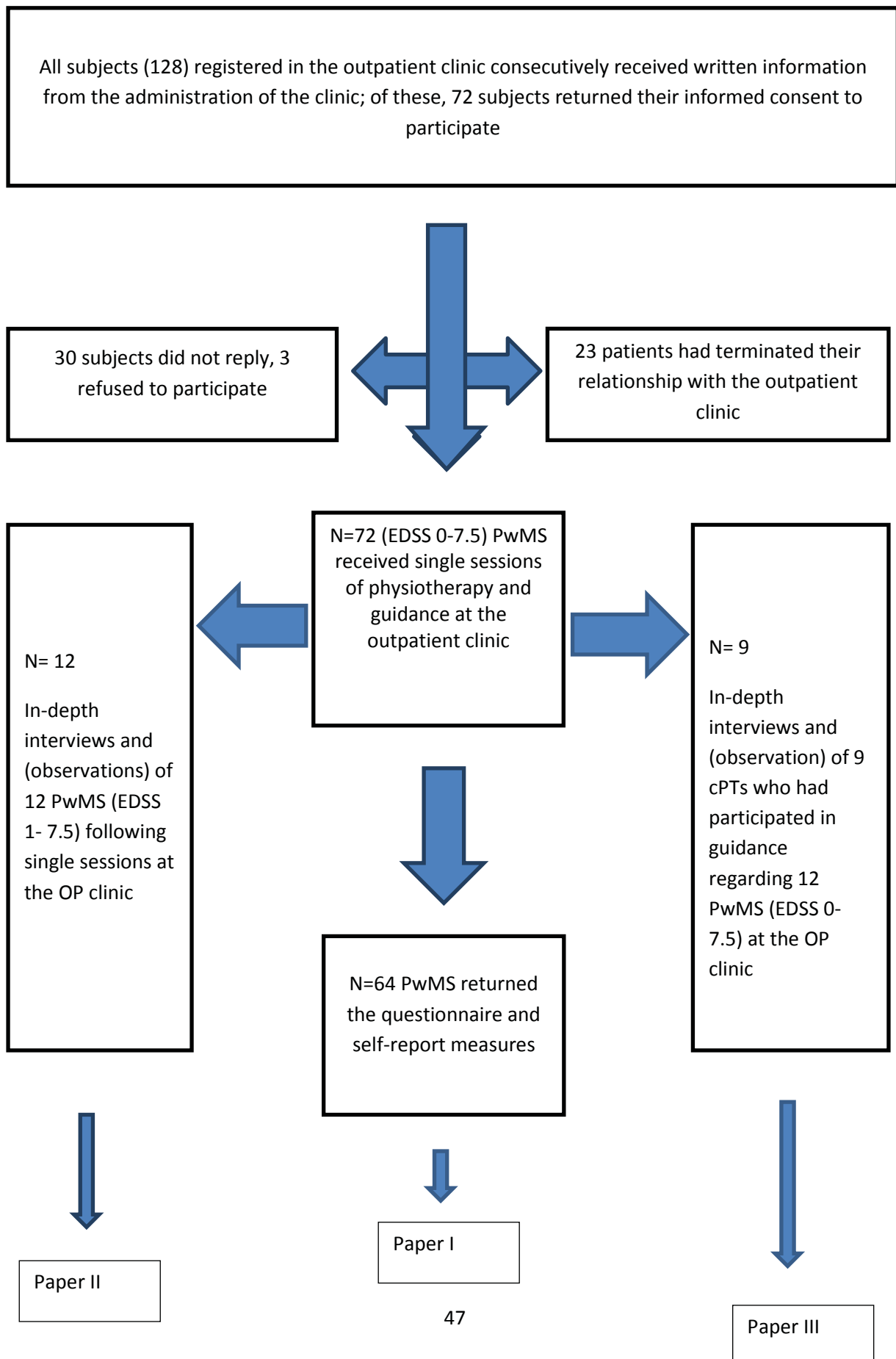
In the parts of the study where qualitative methods were used (Papers II and III), the concurrent use of observations and interviews could be termed as embedded (Blaikie, 2010, p. 224; Polit & Beck, 2012, p. 609), as one method was seen as supplementary to the other. In the overview shown in Table 1, the supplementary method in each study is bracketed. In the quantitative part of the study (paper I), an element of “before and after” was embedded in the cross sectional design to record any perceptions of change regarding standing up/sitting down and walking following the single session. It could be argued that the timespan between “before and after” was very short and was therefore of no interest. However, based on the presented phenomenological framework and the descriptions of changes in performance as prerequisites for motor learning (Shumway-Cook & Wollacott, 2012), information regarding temporary changes may be valuable to record in physiotherapy. Such potential changes are viewed as an outcome of care, which has been shown to be important for patient satisfaction (Hills & Kitchen, 2007a, 2007b).

The different origins of quantitative and qualitative methods demand a pragmatic scientific position for the entire study (Blaikie, 2010, pp. 225-226; R. B. Johnson & Onwuegbuzie, 2004; Shaw et al., 2010). In the quantitative traditions, which are based on post-positivist positions, valid knowledge can exclusively be derived from countable and measurable characteristics of the particular phenomenon (Alvesson & Sköldberg, 1994; Polit & Beck, 2012, pp. 12-13; Thornquist, 2003, pp. 39-41). If human feelings or opinions are to be regarded as a source of knowledge, these components must be transformed into numbers. Examples of this situation involve the questionnaires and self-reporting measurements used in the current study. However, the data produced from these methods are viewed as “soft” data because they are based on the subjects’ own evaluations and not on objective measurements.

On the other hand, qualitative methods have emerged from the philosophical traditions in which human beings are conceived as interpretive, expressive, social and cultural (Alvesson & Sköldbberg, 1994; Kvale & Brinkmann, 2009; Polit & Beck, 2012). These characteristics indicate a focus on structural, contextual and interpersonal relationships from which knowledge could be derived. Human experiences are therefore seen as a vital source of knowledge that is communicated through verbal or bodily utterances that provide valid knowledge when analysed through a systematic hermeneutical process. The hermeneutical position in the present study is based on Gadamer (2004) who emphasises that comprehension is context based and that humans always interpret based on their preconceptions. The position also states that knowledge is derived through a process characterised by being dialectic, in which the researcher influences the phenomenon that is to be investigated and vice versa. Subjectivity and inter-subjectivity are therefore necessary to gain scientific knowledge through a hermeneutic process, which is characterised by systematic and interchanging interpretations of the whole and parts of the material (Kvale & Brinkmann, 2009; Thagaard, 2009).

Based on the predominant use of qualitative methods in the current study and on the theoretical positions elaborated in section 4, the overall position of the whole study was a phenomenological hermeneutical position. In the following sections, an overview of the design (Figure 2) and methods of the entire study is presented.

Figure 2. Overview of the study design



6.3 The participants

The participants for the entire study were 72 PwMS registered at Nordland Hospital Trust's OP clinic for PwMS, nine cPTs, and one oPT. In the following figure, an overview of the participants, design, methods and analysis is presented.

Table 1. Overview of the materials and methods used in the three papers

Paper	<u>Participants</u> N female/male	Design	Method	Statistics/ analyses
Paper I	64 48/16	Cross sectional (Before and after)	Questionnaire Self-report measures	Descriptive statistics Chronbach's alpha Spearman correlation Mann-Whitney Wilcoxon Signed Rank Kruskal-Wallis
Paper II	12 9/3	Qualitative	(Non-participating observation) and interview	Phenomenological hermeneutic content analysis
Paper II I	9 7/2	Qualitative	(Non-participating observation) and interview	Phenomenological hermeneutic content analysis

6.4. Ethics

The study was approved by The Regional Committee for Medical Research Ethics of Northern Norway (P REK NORD 65/2006) (appendix 1) and the Norwegian Social Science Data Services (15105) (appendix 2), and was performed in accordance to the Declaration of Helsinki.

Participation in the study was based on written informed consent (appendices 3, 4). We are grateful for their positive attitudes that enabled this study to be performed, and we have attempted to portray their perspectives and opinions throughout the entire study. In the presentation of the results in the papers, we have distinguished between the participants' statements and the researchers' interpretations. Furthermore, the participants were not identified in these papers, allowing them to remain anonymous. The videos and the recordings of the interviews have been locked, the participants were given letters instead of names, and other identifying signs were removed in the written material. The citations in paper II and III were translated into English while maintaining the core meaning.

In the following sections, descriptions of the methods used in the three parts of the study will be presented. Due to the use of a triangulation of methods, the materials and methods in Paper I are presented separately, while these aspects are described in one section for papers II and III.

6.5 Paper I

6.5.1 The subjects

The aim was to investigate PwMS' satisfaction with physiotherapy consultations in a hospital's OP clinic regarding the process and the outcome of care. Therefore, we chose to include all people above 18 years of age who were diagnosed with MS and registered at the OP clinic. The administration at the clinic sent written information about the study to all 128 registered people; 23 people had moved or had terminated their relationship with the clinic for other reasons. Of the 105 remaining subjects, 72 (69 %) returned their informed consent by mail to the secretary at the clinic, who delivered the form to the project leader. Three people (<3 %) refused to attend, and 30 people (29 %) did not reply. Reminders were not sent because of the limited time frame of the project. The sample included consecutive patients, and the bias-testing showed no differences in age and gender compared to the non-participating patients registered at the OP clinic. Therefore, the sample was considered to be representative of PwMS consulting the hospitals' OP clinics. However, it would have strengthened the study if we had extended the time frame and included more subjects.

To study all 72 participants within the available time period, the subjects who had appointments at the clinic beyond the study time frame were offered an earlier consultation with only the physiotherapist. Hence, 20 (28 %) subjects consulted all three professionals during one day, 12 subjects (17 %) consulted with the physiotherapist and the neurologist, and 40 subjects (56 %) met with only the physiotherapist. From the 72 PwMS who participated in the study, 64 returned the questionnaire and the self-reporting measures. This sample was varied with regard to sex, age, employment status, and ambulatory status; these characteristics are described in detail in paper I. However, the rescheduling of the consultations for 40 of the subjects to an earlier time may have given the person an impression of being particularly important, which may have positively influenced their ratings. On the other hand, the ratings may not have been influenced because appointments in the hospitals are changed frequently.

Although the sample of PwMS was varied in terms of demographics, it was a limitation that the EDSS scores were not available for all of the patients. However, from the registrations in Studies II and III, the EDSS scores ranged from 0-7.5, and it is likely that the same people were included in the response group in Study I. Furthermore, when the sample was divided into subgroups based on ambulatory status, the groups including subjects using walking aids and wheelchairs were rather small. Therefore, the results should be interpreted with caution, particularly regarding the transferability to populations of PwMS having an EDSS score > 7.5.

6.5.2 Measurements

To gain access to quantifiable information from all subjects, we chose to use a questionnaire that recorded patient satisfaction and two self-reporting measurements that recorded perceived perceptions of change in the performance of movement. According to Polit and Beck (2012), surveys are suitable because they provide an overview of evaluations of a phenomenon and transform the experiences to a number on a scale, for example scales of 1-10, 1-5 and Likert scales. Numerical expressions of experiences include a reduction that is based on the assumptions of valid knowledge as something that is measurable. Questionnaires and self-reporting measurements are the most commonly used tools to investigate patient satisfaction and self-perceived effects of therapy because they give an indication from large groups of how a user perceives a service (Polit & Beck, 2012). Although such questionnaires often

contain an open question at the end, they are mainly constructed of pre-determined questions that give data regarding the asked questions and less insight into aspects that were not specifically addressed. Furthermore, how each person comprehends the premade questions is not necessarily the same as what the question was intended to address. The same score does not necessarily mean the same for every person, and there are no opportunities for deeper investigation of what the ratings mean to the individual person because the inter-subjective and relational aspects are extracted when using this approach. These considerations emphasise the importance of using questionnaires and self-reporting measurements that are suitable for the particular purpose and have been developed through a process of validity and reliability testing, and of supplementing such investigations with qualitative research interviews.

The questionnaire - OPEQ

A standardised, validated and reliable questionnaire in Norwegian addressing patient satisfaction with physiotherapy for PwMS did not exist. Therefore, we chose The Outpatient Experience Questionnaire (OPEQ), which is a self-administered questionnaire appropriate for use in OP clinics offering a multidisciplinary approach (including physiotherapy) to people with various somatic diseases (Garratt, Bjærtne, Krogstad, & Gulbrandsen, 2005).

The OPEQ was developed at the Norwegian Knowledge Centre for the Health Services (Garratt et al., 2005 ; Gullvag, Hofoss, & Pettersen, 1998; Pettersen, Veenstra, & Gullvag, 2004). This questionnaire contains 52 items covering the essential aspects of patient satisfaction described by Sitzia and Wood (1997), such as pre-visit communication (including expectations), access to and standards of the clinic, organisation of the clinic, the consultation, after the consultation, and background/demographics. The items use mainly a 10-point scale, but 5-point scales with descriptors at the ends were also used. A final open-ended question requested the subjects' own words regarding their experience at the clinic, hence providing some additional qualitative data (Garratt et al., 2005). However, in the current study, these data were only reported in a summarised form and did not receive the in-depth analysis that was used in Study II.

Garratt et al. (2005) reported reliability results for the OPEQ on internal consistency with a Chronbach's alpha exceeding >0.7 , except for the pre-visit communication scale

(Chronbach's alpha: 0.6), for test-retest correlations of more than 0.7 (Spearman's correlation test), and for hospital standards, which were reported to be 0.65. The test of validity showed that correlations between the OPEQ scores ranged from 0.30 (clinical access and hospital standards) to 0.73 (communication and information), and the scores were found to be significantly related to patients' responses to questions about overall satisfaction, general health and age (Garratt et al., 2005). The OPEQ is a recommended tool and is used extensively at Norwegian hospitals (Garratt et al., 2005).

After discussion with the Norwegian Knowledge Centre, items in the OPEQ that originally addressed experience with all professionals were adapted to ask for the patients' opinions regarding the physiotherapy service at the clinic and not the other professionals. In addition, a question asking about aspects of the medical treatment was removed, and a question regarding instructions for self-assisting exercises was included. Items investigating the subjects' experience from the physiotherapy consultation had the following themes: "how well prepared the physiotherapist was", "understandable language", "professional skills", "care", "politeness and respect", "opportunities to communicate important issues", "information during and after the assessment", "information about self-assisted exercises" and "opportunity to influence further physiotherapy". Items focusing on experience after the consultation asked if the patients had any unanswered questions, if they perceived that they had been incorrectly treated and if the consultation had any impact on their disease and health problems. These answers used scales ranging from one to ten, with one as the worst and ten as the best score or vice versa. Other items, such as "overall satisfaction with the physiotherapy consultation" and "fulfilment of expectations", had scales ranging from one to five, where five was the best score and one was the worst score or vice versa. The OPEQ is presented in appendix 5.

Furthermore, to capture some of the heterogeneity in the sample, we added the patients' "level of ambulatory independence" as a new demographic variable, ranging from "walking independently" to "using walking aids" to "using a wheelchair". This variable was not defined in terms of how much the patient used the wheelchair or the walking aids, but based on how the patient classified his/her own ambulatory status. We consider that the described adjustments of the OPEQ did not affect the validity and reliability of the questionnaire in a substantial way. However, although the OPEQ appeared to address all of the vital elements of patient satisfaction questionnaires used in physiotherapy (Hills & Kitchen, 2007a, 2007b), it

would have been preferable to use a questionnaire designed only for physiotherapy in OP clinics in Norway.

The self-reporting measures

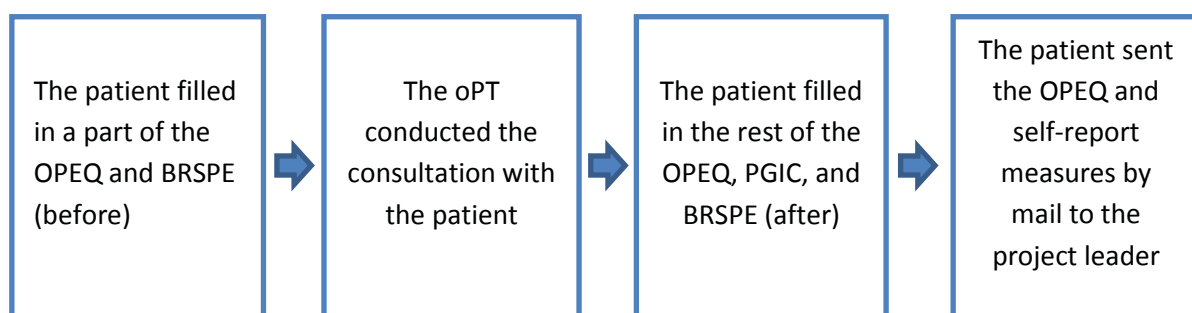
To collect data describing the patients' perceptions of the outcome of care following a single session, we chose measurements that recorded perceptions of change in functional movements. We used the Patient Global Impression of Change (PGIC) form, which has been used extensively in clinical settings, along with the Clinical Global Impression of Change Instrument (CGIC) (Dworkin et al., 2005; J. T. Farrar, Young, LaMoraux, Werth, & Poole, 2001; J.T. Farrar, Troxel, Stott, Duncombe, & Jensen, 2008; Ferguson & Scheman, 2009 ; Smedal et al., 2006). These measurements are presented in appendices 5 and 6. The PGIC is a self-report measure that reflects a patient's belief in the efficiency of the intervention. This measure uses a seven-point scale depicting a patient's rating of overall change. Patients rate their change as "very much improved," "much improved," "minimally improved," "no change," "minimally worse," "much worse," or "very much worse". Farrar et al. (2001) used the PGIC as the criterion measure to validate the 11 point Numerical Pain Intensity Rating Scale (PI-NRS) and found a mean agreement of 78.6 % between change scores of the PI-NRS and categories of change of the PGIC. Furthermore, the authors also noted a Spearman correlation of 0.87 with the CGIC. The CGIC (almost identical to the PGIC) has been tested for test re-test reliability and had a reliability measure of 0.97 when using the tool for assessing physical frailty in a geriatric population (Studenski et al., 2004). In our study, the patients were asked to score their global impression of change with regard to standing up, sitting down and walking after the consultation. These activities were chosen because they are essential in most ADL. On the other hand, even if changes at the activity level are important, it may be ambitious to expect such changes. This measurement should have been supplemented with questions regarding body functions, for example: range of movement, pain, and sensation in the hands and feet. The adequacy of the tool is considered to be sufficient and is previously used in research with PwMS to capture subjectively perceived changes in relevant ADL. However, asking the participants whether they experienced any change may have prompted the patients to score positively, even though the PGIC also captures negative changes.

One of the problems for PwMS is fatigue, which also may be related to motor function. As the sessions were relatively long (90 minutes), we wanted to investigate whether the patients experienced any change in exertion during the named activities following the consultation. We chose the Borg's Rating Scale of Perceived Exertion (BRSPE) (Borg, 1970; Buckworth & Dishman, 2002). This scale is a commonly used self-reported scale regarding walking capacity that ranges from 6 (very easy) to 20 (maximum exertion), and it has previously been used in studies of PwMS (Smedal et al., 2006; R. M. Smith et al., 2006). However, it could be argued that the self-perceived changes also should have been measured in a more objective way using tests for balance and walking distance or velocity. In the current study, there were no resources to conduct the blinded standardised pre – post tests, except for the oPT who conducted individually tailored tests as a part of the consultations. Furthermore, elongation of the 90 minute consultations would have been questionable regarding the danger of fatigue and the huge spectre of disability in the sample.

6.5.3 Procedures

In the following figure, an overview of the procedures is presented to demonstrate how the above described physiotherapy consultation and the measurements used in the study were coordinated.

Figure 3. Overview of the procedures in each session of physiotherapy in the study



After having performed individually chosen balance and walking tests, the oPT provided the BRSPE (before) and the first part of the OPEQ to the patients. In a private room, the subjects rated their perceived exertion before the consultation (BRSPE) and their expectations of the

consultation with the physiotherapist (OPEQ) and put the ratings into an envelope addressed to the project leader (BN) before the described physiotherapy consultation proceeded. Immediately after the consultation, the oPT gave the patients the last part of the OPEQ, the PGIC and the BRSPE to record perceptions after the consultation. The subjects completed these questionnaires either in a private room at the clinic or at home and returned the papers anonymously by mail to the project leader, who had no relationship to the subjects. The personal distribution of the self-reporting measures and the questionnaire may have caused the participants to feel obligated to return their responses (there was a high response rate of 89 %) and perhaps to give more positive ratings. To eliminate this personal factor, the OPEQ and the self-reporting measures should have been delivered by mail, but doing so would most likely have resulted in a lower response rate and less data.

6.5.4 Statistics

Satisfaction data usually have markedly skewed distributions, which occurred with the data from this study. Because of the skewed distribution and small-sized subgroups, non-parametric statistics were chosen for analysing the data (Siegel & Castellan, 1988).

The OPEQ's 11 items dealing with different aspects of the physiotherapy consultation were first analysed separately, and then after reversing the variables with opposite scales (one in one variable having the same meaning as ten in another), the results were compiled into a single group. After removing three items³, the internal consistency of the new variable "Satisfaction with the physiotherapy consultation" increased from a Chronbach's Alpha of 0.71 to Chronbach's Alpha of 0.85. We used the constructed variable to examine a possible relationship between "satisfaction with the physiotherapy consultation" and (i) the level of ambulatory independence, (ii) expectations and (iii) the type and number of professionals that the subject had consulted at the outpatient clinic using the Kruskal-Wallis H test. Furthermore, a possible relationship between the constructed variable and gender was explored with the Mann-Whitney U test, while the relationship with age was investigated with

³ How did the physiotherapist talk to you? Did you receive sufficient information about how your condition could develop in the near future? Were you met by respect and politeness? (continuous scale)

the Spearman's Rank correlation test. The Wilcoxon Signed Rank Test was used to study potential changes in subjectively experienced effort with regard to walking and standing up/sitting down recorded at the beginning and end of the session. A significance level of 0.05 was chosen. The statistical analyses were performed with the IBM SPSS software (PASW Statistics 17.1).

The present study had a predominance of highly positive ratings, which is common for studies of user satisfaction. In addition to raising questions about the validity of the data, the skewed distributions may have reduced the variance and lead to type II errors. The high ratings may have been due to the novelty of the service as suggested in other reports (Sitzia, 1999; Williams, Coyle, & Healy, 1998). In addition, the chronic nature of the disease may have generated hope for future help, resulting in an obligation to show gratitude to secure continued physiotherapy service at the clinic. Therefore, the results must be interpreted with caution and will be validated and complemented by the results from studies II and III.

6.6 Papers II and III

6.6.1 The informants

In Study II, a purposive sample of 12 PwMS from the total group of 72 PwMS was chosen. The research question explored the significance of perceptions of movement; variations in ambulatory status and the duration of MS were considered the most important factors. Based on the large sample (72 PwMS) who had returned their consent, the recruitment was performed by the project leader in collaboration with the oPT who had the necessary demographic information regarding age, gender, ambulatory status, type of MS and time since diagnosis. The sample was variable regarding these criteria, and an overview of the patient demographics is presented in Paper II.

In study III, the sample included nine cPTs who had attended one or two professional guidance sessions with the oPT regarding different patients. Based on the research question, variability in the cPTs' professional background and in the EDSS level among the PwMS involved in the guidance sessions was emphasised. The recruitment was performed by the

project leader in collaboration with the cPT who had the sufficient knowledge about the cPTs and the patients to address the inclusion criteria. The sample of cPTs constituted seven females and two males with varying levels of experience in the treatment of PwMS (2->10 years), postgraduate education in neurology, and experience practicing in urban and rural areas. The PwMS to whom the clinical guidance was directed had varied EDSS scores, times since the onset of the disease, types of MS, ages and genders, as described in Paper III.

The samples in Paper II and III were purposively selected to include people with first-hand experience with the issues in question, as recommended by several authors (Kvale & Brinkmann, 2009; Malterud, 2001, 2011; Polit & Beck, 2012; Thagaard, 2009). The samples are relatively small, and questions regarding achievement of saturation are adequate. Saturation is a guiding principle implying sampling to the point at which no new information is obtained and redundancy is achieved (Polit & Beck, 2012, p. 521). However, small samples do not necessarily mean lack of saturation. According to Polit and Beck (2012, p. 521), the key issue is the generation of enough in-depth data that can illuminate patterns, categories and dimensions of the phenomenon under study, or to produce a material characterised by richness as emphasised by Malterud (2001, 2011). Some authors suggest including 1-10 informants for qualitative studies because this number allows for the necessary in-depth analysis (Starks & Brown Trinidad, 2007). The material in the current studies (II, III) was characterised by fruitfulness, which may be due to appropriate or “good” informants who were able to share their reflections as mentioned by Polit and Beck (2012), and to the use of both observations and interviews in the data production. However, a larger sample may have added new themes into the material, and the samples did not include PwMS with an EDSS score worse than 7.5 or people with major cognitive dysfunctions. These limitations must be considered when evaluating the transferability of the results.

6.6.2 Data production

The research questions in Studies II and III explored PwMS’s and cPTs’ experiences with physiotherapy and guidance in the OP clinic and, in particular, the significance of body and movement in these settings. For PwMS, the experiences regarding their own body were requested; for the cPTs, the focus was on the information they understand and learn from

guidance during the assessment and treatment to optimise the movement performance of PwMS. Interviews were used because they derive knowledge from detailed meaningful descriptions and reflections regarding first-hand experiences with a particular phenomenon, as described by several authors (Kvale & Brinkmann, 2009; Malterud, 2001, 2011; Thagaard, 2009).

In the current study, an interview was considered a professional, structured and purposive conversation in which knowledge was generated or constructed from the interaction between the interviewer and the interviewee as described by Kvale and Brinkmann (2009, p. 2). The interactive process was based on the phenomenological and hermeneutical understanding of human beings as experiencing, expressing and participating in situations that are meaningful to them (Gadamer, 2004). However, movement (especially one's own movement) is not usually perceived consciously; therefore, it may be challenging to create conversations in which an interchange of reflections regarding perceptions of movements can easily evolve. Therefore, non-participatory observations of the guidance sessions were made prior to conducting the interviews for both Study II and III. The observer used a hand held video-camera to preserve the observations and to enable the observer to capture an optimal position that changed throughout the consultations. Both the observations and the interviews were conducted by the first author of the papers (BN), who is an experienced physiotherapist in the treatment of PwMS and had no relationship to the informants.

The observations

The material in Study II contained videotaped non-participating observations of seven of the 12 PwMS; each lasted 70-90 minutes and an observation guide was used (appendix 8). As described in Paper II, not observing all of the informants could be a weakness of the study. However, after observing the majority of them, the interviewer gained sufficient insight to conduct the interviews with the non-observed informants as well. In Study III, nine videotaped non-participating observations that lasted 60-70 minutes each were performed, and an observation guide was used (appendix 9).

The observations were conducted in natural clinical settings, either at the OP clinic or at the cPTs' workplace, and were performed in accordance with recommendations by Polit and Beck (2012) and Heath, Hindmarsh, and Luff (2010) to be as professional and discrete as possible. The professional background of the observer made it easy to follow the participants in terms of positioning to capture the participants' verbal and facial expressions and interactions. The zoom function was used occasionally to, for example, focus on the oPT's handling of the patient, even though a reduction of the data occurred. The observed interactions were disturbed as little as possible by being quiet, avoiding gaze contact with the participants and moving slowly when the position needed to be changed. As highlighted by many authors, the researcher's presence with a camera makes the situation different from usual and will influence the interaction that is the target of the observation to some degree (Fangen, 2010; Heath et al., 2010). However, some of the participants spontaneously commented during the debriefing afterwards that they had nearly forgotten both the observer and the camera. Similar experiences have been reported in other studies (Heath et al., 2010; Pedersen & Normann, 2012; Øberg, 2008). Hence, the observations are considered to accurately reflect clinical practice as it is usually conducted, which strengthens the validity of the study. Short field notes were taken immediately after the observations to preserve the first impressions. These notes included sequences in the consultations where the patients expressed engagement or disengagement and positive or negative changes in perceptions or performance of movement because these aspects were relevant to the research focus of both Study II and III. These notes were used in the subsequent interview of the particular patient and as a general background for interviews with the three informants that had not been observed (Study II). Based on the field notes and the videos, the observer made written summaries of the observations.

The interviews

The interviews were as recommended by Kvale and Brinkmann (2009) performed in a sheltered room and in a relaxed atmosphere at OP clinic (Paper II) or at the cPTs workplace (Paper III). The interviews were recorded and lasted from 42-90 minutes. Some were performed immediately after the clinical session, while the rest were conducted within one week. The timespan was convenient to the informants and aimed to capture both immediate experiences and subsequent reflections. Prior to the interviews, the field notes were reviewed.

When the interviews were conducted on subsequent days after the observation, the video was also reviewed. The observations and the field notes, together with the interviewer's professional background, made it easier to ask concrete open-ended questions. This background facilitated follow-up questions that encouraged the PwMS to verbalise aspects of perceptions of their own body and movements. Similarly, the shared experience from the guidance sessions facilitated the conversations and enabled the cPTs to describe aspects of experiences with clinical guidance that also included perceptions of body and movement. The interviewer's knowledge from the observed clinical encounters together with the premade theme guides (appendices 10 and 11) facilitated the instrumental dialogue as described by Kvale and Brinkmann (2009). Based on this background, the conversations produced nuanced, detailed and meaningful descriptions from the informants and allowed the interviewer to understand what the informants were talking about in the interviews. The fact that the informants knew that the interviewer was an experienced physiotherapist and in most cases had seen the session they were discussing appeared to be a positive factor, as the informants appeared engaged and confident during the interviews. These elements are described as being important for producing sound data (Kvale & Brinkmann, 2009; Polit & Beck, 2012).

During the interview, communicative validation (member checking) (Kvale & Brinkmann, 2009; Polit & Beck, 2012) was performed by rephrasing the informant's words and asking the informant whether the rephrased interpretation was correct. In addition, questions were asked that invited the informant to rephrase his/her own descriptions to ensure consistency throughout the conversations. The interviews were transcribed by the interviewer with a modest interpretation that emphasised a preservation of the meaning of expressions as recommended by Malterud (2011).

6.6.3 Analyses

The transcribed interviews, the video-tapes, the video summaries and field notes constituted the material in these two parts of the study, of which the interviews were the main source. However, in study II, summaries of the observations constituted an integral part of the material underpinning the themes, while the observations in Study III more explicitly served

as a background for the analyses of the interviews. The materials in both studies were analysed by the first author of the papers in collaboration with the last author (SM), who is a physiotherapist with experience using qualitative methods and in health promotion. This process was complemented by the other co-authors, KWS, who is a psychologist, and RS, who is a neurologist. To strengthen the quality of the material, the first author (BN) re-listened to the interviews while reading and slightly adjusting the written material, and viewed the videos several times before the systematic analysis was performed. The last author (SM) of the papers read all the interviews and viewed some of the videos to check the internal validity of the interpretation, and agreement between the two authors was found. In paper III, the second author (KWS) served as an “outsider” (Polit & Beck, 2012) and read all the interviews and reviewed the analyses; this process resulted in a high degree of agreement regarding the interpretations. The third author of the papers (RS) reviewed the final results.

As described in the qualitative methods (Heath et al., 2010; Kvale & Brinkmann, 2009), the preliminary analysis began with the interviews and observations. The systematic organisation of the material, followed the process of content analysis inspired by Kvale and Brinkmann (2009) and Lundman and Graneheim (2004) for Paper II, and Malterud (2011, 2001) and Kvale and Brinkmann (2009) for Paper III. The two different methods of systematic content analysis were described in the respective papers, and the common principles are described in the following sections.

An hermeneutic approach was used in which the whole interview material was read to obtain an impression of the general content (preliminary themes), followed by an interchange between studying the whole (one interview/all the interviews) and parts (parts of the interview/one interview). In addition, the literature was studied in between reading the material to address the theoretical framework and to unfold the hidden or deeper meaning. Furthermore, the material was organised in a systematic way (de-contextualisation) into units of meaningful expressions. The statements were condensed while maintaining the core meaning and were further reduced into codes or key words “representing” the meaningful units. The meaning condensation was data driven, guided by the actual research question and informed by the presented theoretical framework and was the first level of abstraction in the

process as described by (Kvale & Brinkmann, 2009). Similar codes were then organised into categories (second abstraction level), which subsequently were organised by content into themes (third abstraction level). This structure of the analysis was a “curved journey” of discussions, adjustment and refinement through the entire process. Finally, the themes were then re-contextualised or seen in relation to the original interview material, as described by Kvale and Brinkmann (2009) and Malterud (2011).

The goal of the analysis was to derive knowledge that exceeded the actual informants or situations. In qualitative research, the interpretations allow for such transference of results to occur, not the descriptions of the patterns in the data (Thagaard, 2009, p. 207). In the present study, the interpretation was conducted systematically by applying the three levels of interpretation as described by Kvale and Brinkmann (2009, pp. 213-217). First, we reformulated, in a condensed form, the informants’ perception of the meaning of their statements, which we member-validated with the research group. The next level of interpretation, the critical common sense understanding, goes beyond the self-understanding expressed by the informants by including a wider frame than the informants. This level was achieved by the authors critically discussing and questioning the condensed material while relating it to the research questions and to general aspects of physiotherapy service in OP clinics for PwMS. The common sense level was validated through discussions within the research group and the audience, and the latter was based on recognition (Kvale & Brinkmann, 2009). Recognition refers to the reader’s ability to identify what the text conveys either based on the reader’s experience or familiarity with the phenomenon described in the text or because the reader is able to understand general trends and features within the described phenomenon (Thagaard, 2009, pp. 209-210). The two abstraction levels elaborated above were presented in the result section in papers II and III.

The discussion section in these papers represented the third analytic level. This part contained the theoretical understanding of the results, also termed as the theoretical generalisation (Kvale & Brinkmann, 2009). This level of interpretation is likely to go beyond the previously mentioned levels because a theoretical framework is applied for interpretation of the material. In the current study, phenomenology of the body complemented with neuroscience and

practice knowledge were applied as the framework for the interpretations. The analyses were conducted in accordance with Kvale and Brinkmann (2009) and underwent peer validation in the research community. Other authors describe this process as analytic generalisation (Polit & Beck, 2012, p. 525; Thagaard, 2009, pp. 207-211), in which a key element is the logical relationship between the raw data and the abstractions and interpretations. Theoretical generalisation is based on the particular study's ability to convey an understanding of basic features concerning the phenomenon in question (Thagaard, 2009, p. 208). As the material was produced from informants who have first-hand experience with the phenomenon in question and the analyses extracted knowledge concerning general aspects of a particular phenomenon, transference of this knowledge to other similar situations and populations is according to qualitative methods possible (Kvale & Brinkmann, 2009; Polit & Beck, 2012; Thagaard, 2009).

6.7 Reflexivity; closeness and distance

Triangulations of methods were used in the current study, and reflexivity regarding the researcher's position was important to consider for the quantitative and qualitative methods.

In paper I, the researchers distance from the subjects was described, based on the quantitative methods' assumptions that the researcher should be in a neutral position regarding the phenomenon that is to be investigated. It may be uncommon in this tradition to reflect on the researcher's preconceptions regarding the particular phenomenon because previous studies serve as the background for a study. However, based on the post-empirical tradition, the researcher will always have her/his preconceptions incorporated (Thornquist, 2003, p. 197). Accordingly, the researcher will influence what research questions are asked, which measurements are chosen, and how the results are interpreted. For example, the choice of the self-report measures and questionnaire and the adaptations made to these materials for the current study were based on preconceptions from the researcher's experience as a physiotherapist and on the cited literature. Through the entire research process, distance between the participants (subjects) and the researchers was maintained, in particular, between the first author and the participants. Furthermore, the data were entered by a research secretary, and the statistical analyses were conducted in collaboration with the last author of

paper I (KWS). None of these persons were involved in the OP clinic. Therefore, in the current study, the recommended distance in quantitative methods were followed (Polit & Beck, 2012) with an awareness that the researcher's position can never be completely neutral.

Qualitative research is characterised by closeness to the phenomenon that is to be investigated. The good dialogue in a research interview demands intimacy and interaction. In non-participating observation settings, the researcher becomes a part of the actual situation through his/her physical appearance, positioning, gaze and camera direction. Closeness and sensibility in the actual situations are seen as a prerequisite for producing valid and reliable data from these research methods (Kvale & Brinkmann, 2009). These conditions were met in the current study through the first author's long-time experience with physiotherapy for PwMS and theoretical knowledge from the MS research field. The third author (RS), the neurologist, was also close to the field, which was relevant for the analyses. These two authors had relationships to the hospital in which the study was conducted. These positions represent a "double" closeness to the research field that calls for special care regarding the reflexivity of the researchers' role, particularly the first author who performed the interviews and observations. To achieve valid results, the intimacy must be balanced with distance, which will be discussed in the following sections.

The first author's physiotherapy background was considered as advantageous to enable the interviewer to ask relevant questions and to focus the video camera at vital aspects of the interaction in question. The interpretations of what the PwMS and the cPTs discussed evolved from this background knowledge which Paulgaard (1997) terms as *positioned insight*. This insight augmented the sensibility in terms of what in the observations needed to be explored in the subsequent interview and of what relevant follow-up questions to ask in the interviews. The disadvantage of having such positioned insight was that it was more challenging to achieve distance during the data production phase. There will always be aspects that are taken for granted, or aspects of the pre-conceptions as a socialised physiotherapist that are impossible to verbalise and bring to consciousness. This risk is often termed *home-blindness* (Paulgaard, 1997; Wadel, 1991). In the current study, there may be some unasked questions because the interviewer took some aspects for granted, and similarly, there may have been

some less or non-described answers from the informants because they took for granted that the interviewer understood their meaning. The interviewee knew from the information letter that the interviewer was an experienced physiotherapist.

To establish the best possible analytical distance, pre-understandings of the research field were optimised through a review of the literature in the field and by forming an interview and observational guide, as recommended by several authors (Kvale & Brinkmann, 2009; Malterud, 2001, 2011; Polit & Beck, 2012). Furthermore, the researcher tried to behave in a professional, trustworthy, open, curious and clear way during the interviews and aimed to set aside the presuppositions as much as possible. However, the informants may, unconsciously or consciously, have given answers that they thought the interviewer wanted to hear based on the asymmetry and relationships established in the situation. Effort was made to minimise this effect during the interviews by being aware of the power position of the interviewer, by encouraging the informants to speak freely and by rephrasing their answers to challenge their statements in a polite way while encouraging expression of their genuine opinions. To summarise, the positioned insight was regarded as an advantage when balanced by distance, which was accomplished during the data production for the current study.

Analysis includes using perspectives as lenses and applying specific systematic procedures to understand a phenomenon (Kvale & Brinkmann, 2009). Throughout this process, an open-minded approach to the material was taken, in which both positive and negative experiences among the informants were sought. Based on the closeness for two of the authors, particular attention was paid to the risk of favouring positive elements. To enable the text to reveal the hidden or deeper content, critical questions were asked concerning the text or statement as recommended by Kvale and Brinkmann (2009). This process required a broadening of the traditional bio-socio-medical based understanding of physiotherapy to apply a framework from phenomenology embedded with neuroscience and movement science, complemented with the theory of practice knowledge. The integrated theoretical framework enabled the necessary analytical distance to be established, well aware that different perspectives will elucidate different aspects of a particular phenomenon. The distance was strengthened by the background knowledge and varied affiliations of the co-authors. The discussions with the co-

authors during the analyses were vital and represented another background for understanding, and hence served to strengthen the rigour of the analyses. The lack of discrepancies in the interpretations that occurred in the current study strengthened the validity and reliability of the results. Furthermore, the results from studies I and II have been presented at three international conferences and the questions and discussions that occurred in these settings have strengthened the interpretations.

6.8 Validity, reliability – trustworthiness

Research involves a systematic production of knowledge following specific guidelines. To ensure that knowledge from the current study can be trusted, all phases in the research process were described in as much detail as possible for each of the three studies. Because different methods were used among the three studies, the following considerations will be divided into discussions regarding the quantitative and qualitative methods.

Reliability in quantitative methods refers to the accuracy and consistency of information obtained in a study and includes both the procedures and the methods to measure variables (Polit & Beck, 2012). In previous sections, the sampling was described, the measurements (including reliability and validity testing) were reported, and the procedures and statistical analyses performed were described to offer transparency in the process. Furthermore, considerations regarding all of the steps in Study I are described, and with the described limitations in mind, the results are considered to be transferable to other similar populations and settings.

In qualitative research, achieving transparency during the process is equally important. However, transparency is not meant to enable someone else to replicate the study, but to enable the reader to follow the process and evaluate whether the interpretations are probable or logical (Kvale & Brinkmann, 2009; Malterud, 2001, 2011; Polit & Beck, 2012). Other terms for reliability and validity are often used, such as trustworthiness.

Trustworthiness encompasses several dimensions: credibility, transferability, confirmability, and dependability (Polit & Beck, 2012). Credibility in the present studies (II and III) was achieved through a detailed description of preconceptions, the research process and reflexivity regarding all of the steps in the studies. Transferability was accomplished through systematic analyses using theoretical frameworks as analytical tools. Thick descriptions are often mentioned as a prerequisite for transferability, and this term refers to a rich and thorough description of the research setting, study participants, nuanced material, and a detailed account of the analysis (Polit & Beck, 2012, p. 526). The proximal similarity model developed by Donald Campbell suggests that although generalisation can never be made with certainty, the results can be transferred to those people, places and contexts that are most like those in the focal study (Polit & Beck, 2012, p. 525, referring to Campbell, 1986). Confirmability is accessible for the readers of the present studies through the presentations of thick (comprehensive, nuanced, detailed) descriptions in the result sections in papers II and III. The result presentations enable the reader to critically evaluate the interpretations, given that the chosen theoretical framework is applied as an analytic “tool”. Dependability refers to results that are consistent and stable (Polit & Beck, 2012). Both communicative validations during the interviews and the discussions among the research team produced consistent results. Based on these and the previous methodological considerations, the insights from studies II and III appear to be transferable to similar populations and situations and may be of relevance for general aspects in physiotherapy.

The triangulation design used in the present study, allows for the results from the qualitative studies (II and III) to explain the quantitative study (I) (Blaikie, 2010; Polit & Beck, 2012). Hence, validation was performed by inter-relating the results, which strengthened the entire study. Aspects regarding this process will be further elaborated in the General discussion.

7. Summary of results

7.1 Paper I

The aim of this part of the study was to investigate PwMS's satisfaction with single physiotherapy consultations in a hospital's OP clinic regarding the process and outcomes of care; the latter was accomplished by focusing on perceptions of change in balance and walking following single consultations. The data from the OPEQ (a score of 10 was the best) showed the following results:

- Very high satisfaction with the staff collaboration (mean 9.4, SD 0.5), the organisation of the service (mean 9.6, SD 1.6), time for conversation with the physiotherapist (mean 9.4, SD 1.9) and pre-visit information regarding physiotherapy (mean 8.4, SD 2.5).
- High expectations regarding the consultation with the physiotherapist; 49 subjects (78 %) had very high to moderately high expectations, and 14 (22 %) answered: "I do not know". The subjects' reported levels of ambulation were not associated with their expectations of physiotherapy.
- Very high satisfaction with all aspects of the physiotherapy consultation (information, interpersonal relationship, clinical skills, and guidance) (mean 9.4, SD 1.0) regardless of their age, gender, expectations, level of ambulatory independence, and if they had seen one or two additional professionals on the team during one day.
- Very high satisfaction after the physiotherapy consultation (mean 9.4, SD 0.9); nearly half of the subjects reported some degree of impact on how they perceived their disease or health problem.
- Half of the sample (n = 31) reported that the physiotherapy consultation was as expected, whereas 13 (21 %) claimed that it was somewhat better, and 18 people (29 %) rated it as "much better" than expected.

The results based on the ratings from the PGIC showed that 35 subjects (57 %) reported minimal to great improvement, whereas 26 (43 %) reported no change in walking and standing up/sitting down. Subjects who used walking aids (n = 7) reported greater perceptions of improvement than those using wheelchairs (n = 8) (chi-square 8.45, p = 0.015).

The results based on the ratings from the BRSPE showed a significant change from more to less reported exertion during standing up/sitting down and in the walking test at the end of the session (Wilcoxon signed-rank test, Z = -2.58, p = 0.010).

7.2 Paper II

The aim in this study was to explore the significance of movement during single physiotherapy consultations in a hospital's OP clinic and particularly to investigate what perceptions of movement may mean for PwMS' insights into their movement disturbances.

The data produced the following results:

- PwMS's perceptions of specific movement during the consultations, embedded in the oPT's explanations focusing on inter-relating the patient's sensory-motor dysfunctions to the patient's problems with ADL, expanded the PwMS's knowledge regarding their own situation.
- The oPT's use of a handling and demonstrations in the interactions with the patients informed the patients more than words alone. PwMS's active performance of movement and the perceptions of self-movement during the consultation enriched the verbal dialogue with the oPT.
- Self-perceived changes in the quality of movement, mostly improvements but also worsening during the consultation, were reported. Examples of improvement were better physical contact between the feet and the floor, better flexibility in the ankles/feet when standing, a more upright position and a perception of easier balancing and walking. Worsening was associated with tiredness and heavy legs while walking at the end of the session. The improvements surprised the PwMS and appeared vital for gaining insights regarding limitations and possibilities of motor function. Furthermore, the perceptions of improvement augmented the PwMS's attention during the situations and increased the credibility attributed to the advice given by the physiotherapist regarding self-assisted exercises.
- Practical hand-on guidance in self-assisted exercises was reported as a vital element in the session, particularly for performing new and more optimal movement strategies. The less disabled patients considered that they could profit from this advice, while the more disabled patients did not consider themselves as capable of doing the exercises on their own.
- Access to physiotherapy in the OP clinic from the initial phase and throughout the course of the disease was requested.

7.3 Paper III

In this study, we aimed to investigate what the cPTs experienced as significant elements in the clinical guidance sessions at the OP clinic and their considerations regarding implementation in subsequent treatments. The findings are as follows:

- The cPTs highlighted participation in authentic movement analysis of a familiar patient as vital. An important aspect of this joint assessment, performed through observation and handling was the oPT's verbalised reflections while handling the patient.
- The cPTs emphasised the importance of participation in exploratory treatment aiming to achieve improvement in motor performance accompanied by verbal reflections and discussions during the action. Observations of changes in performance of balance and walking during the session surprised the cPTs and appeared important both for strengthening the movement analyses and for providing directions for further treatment.
- Reflections on action, without the patient present, appeared to be essential for the cPTs' professional development. Particularly, clinical reasoning regarding the hypothesis of why the patient was moving the way he/she was and goal-setting were reported to be fundamental.
- Experienced cPTs expressed capability for implementing some of the advice in subsequent treatments, which may strengthen the continuity and quality of care; however, the less experienced cPTs found this process to be difficult.
- Supervision while the cPTs handled and treated the patient was requested from the cPTs as was more plain language in the patient reports.
- Guidance in situ was reported to be more valuable to cPTs than written reports.
- Structural elements of significance highlighted by the cPTs were as follows:
 - The cPTs argued for their need to know the scheduling of the patient at the OP clinic to request clinical guidance when they felt the need for it. There was a request for mutual information flow wherein the perspective of the cPT was implemented.
 - The cPTs emphasised a need for complementary learning arenas, such as professional networks, workshops emphasising clinical skills, and the inclusion of more guidance or supervision in hands-on treatment.

8. General discussion

The overall aim of this study was to derive new knowledge from PwMS's and cPTs' experiences with physiotherapy and clinical guidance in an OP clinic for PwMS to provide a scientific basis for physiotherapy in these settings and explore the theoretical framework for neurological physiotherapy. The results from the three parts of the study revealed different aspects of these phenomena. In accordance with triangulation designs (Blaikie, 2010; Polit & Beck, 2012), these results were analysed in relation to each other; a search for congruency and complementarity among the results aimed to generate new insights related to the overall purpose. An overview of this analysis is presented in appendix 12.

The analysis led to organisation of the discussion as follows: *Body and movement in sense making and professional development*, underpinned by considerations regarding *participation, perceptions of change and sense making* and *knowhow and continuity of care*. These topics will be discussed in context of the results from the three studies and the presented theoretical framework, along with relevant reports from the literature. These theoretical considerations are followed by an incipient integrated theoretical foundation for neurological physiotherapy, concluding insights and implications for practice and further research.

8.2 Body and movement in sense making and professional development

8.2.1 Participation

A main result in Study I was the reported high satisfaction with all aspects of the physiotherapy consultation (OPEQ), regardless of age, gender, and ambulatory status. With the previously mentioned limitations in mind (section 3.2, 6.5 and paper I), we concluded in Paper I that the reported high pre-expectations, fulfilment of prospects, and very few ratings of moderate satisfaction strengthened the results. We suggested that relational factors, the content of the sessions and the proceeding guidance of the cPTs produced these ratings. These conclusions were supported by the results in Study II, where several of these aspects were detailed described by the informants.

The questions in the OPEQ addressed information and inter-personal elements of the physiotherapy consultation, allowing us to detect the patients' evaluations of participation aspects, focusing on the dialogue between the oPT and the patient. Verbal utterances, gesticulations and facial expressions are usually defined as the elements of communication (Thornquist, 1998, 2009). However, the results from papers II and III highlighted the significance of body and movement as an integral part of communication in clinical settings for PwMS and for the cPTs in professional guidance. This finding is in accordance with Thornquist's critique of the narrow conceptions of communication mentioned above. In the present studies (I, II), participation through movement and perceptions of movement was reported to enrich what the patients and cPTs gained from the conversations with the oPT.

Body, movement and words

Based on Merleau-Ponty's ([1962] 2008) conceptions of the body, expressions through movement and perceptions while moving constitute an assimilated part of the inter-subjective process between the patient and the oPT. Therefore, the patient's performance of activities, such as walking, serves as a way to communicate more than just whether one is able to walk to the window or not. We consider the patient to express aspects of resources and limitations regarding the activity in question as well as emotional aspects. The latter is described in previous studies of psychosomatic physiotherapy (Eckerholdt & Bergland, 2006), while other aspects have been less investigated. In accordance with Merleau-Ponty's theory, we argue that aspects of the present body, in which the habitual body or the lived experience is embedded, are communicated to the physiotherapist through postural expressions, selectivity and coordination of movements. The neurobiological correlate for these utterances includes interactions between the person's present body schemes and executive networks in the CNS, in which exacerbations and learned non-use due to MS are integrated. Characteristics regarding performance of movement are then seen as inseparable from the moving subject.

Gathering information from the patient's perspective is important for the physiotherapeutic assessment of PwMS. In the literature, subjective information from the patient is predominantly related to verbal communication, while aspects of the body are usually considered separately (Carr & Shepherd, 2010; De Souza & Bates, 2011; Gjelsvik, 2008;

Shumway-Cook & Wollacott, 2012). Observation and analysis of movement have been associated with movement sciences, standardised tests and neurological symptoms in the mentioned literature. Merleau-Ponty's theory of the body allows for disturbances of movement in PwMS to be understood as more than reduced range of movement, disturbed sensibility, reduced strength or dys-coordination of the body as a biomechanical system. The framework allows for an understanding of the patient's disorders as a change in their embodied intentionality, wherein sensory-motor and perceptual networks interactions are embedded, and provides some of the premises for SO and SA that determine how PwMS can engage with the world.

As the task usually is in the focus for our attention during ADL and not how we move to accomplish it, there may be limitations in terms of what could be expressed verbally by the patients concerning movement resources and limitations. Based on phenomenology of the body, verbal information from the patient is considered to be dominated by the person's body image and conscious opinions regarding his/her dysfunctions in ADL. In accordance with Leder (1990), that information is influenced by perceptions of dys-appearance or the body in third person (an "object"), which is relevant information for the physiotherapist. However, the surprises regarding unknown restrictions and possibilities that the patients and the cPTs (particularly the less experienced) described when physical interaction (hands-on techniques) was used to derive information during the session, indicate that use of verbal information alone may conceal resources and information. The oPTs' attention to entities or "gestalts" of movement and assessment through hands-on facilitation techniques while the patient was moving (walking, transferring weight in sitting or standing, and reaching) imply access to non-conscious or pre-reflectively based information of the patient's movement capacities during an activity. Information communicated through hands-on interactions allows the embodied self's utterances to be included in the inter-subjective process between the physiotherapist and the patient. Similar to verbal communication, physical interactions demand an embodied sensitivity and the attention of the collaborating subjects to enable a "conversation" to take place. The current study highlights the integration of bodily dimensions in the inter-subjective process during physiotherapy, and not only the cognitive and psychological dimensions which are more often emphasised in physiotherapy (Carr & Shepherd, 2010; Shumway-Cook & Wollacott, 2012). Integration of the phenomenology of

the body and movement sciences allows for extension of how these embodied utterances are interpreted and met in the clinical settings.

Words, gesticulations, expressions through performance of movement and physical interactions communicate different aspects of information in clinical settings. Expressions and perceptions through body and movement communicate pre-reflective aspects of the embodied self's resources and limitations, while words allow for the reflective aspects to be exchanged. The present study emphasises that integration of these ways of participation appears to be important both in the clinical setting and in professional guidance.

Levels of participation

Independent movement while problem solving a task is often associated with active participation of the patient and vice versa when physiotherapeutic approaches involving hands-on techniques are conducted (Carr & Shepherd, 2010). In the current study, movement was performed in various ways; movement was induced by the oPT combined with specific mobilisation of tissue, induced through the oPT's hands-on facilitation techniques, and independently performance of various tasks. Based on the framework underpinning the present study, we understand these ways as different levels of active participation of the patient as an embodied self.

Adjusted passive movement combined with specific mobilisation of the skin, muscles and tendons for an attentive patient will involve the perception of me being touched and me being moved. Such handling is aligned with the activation of sensory and perceptual networks that support the patient's SO or the pre-reflective awareness of the embodied self's movement, which may be brought to a reflective conscious level through the patient's attention and focus towards the activity. However, when the physiotherapist is less attentive or not "tuned into" the patient while handling him/her, the patient's degree of participation most likely will be lower. We understand the latter situation, in which joint attention and co-construction of meaning are lower, to be more associated with Leders's (1990) term dys-appearance or the physiotherapist's passive movement of the body as "an object". These considerations indicate

that joint attention between the oPT and the patient, particularly directed towards perception of their own and the other's movement, is a key element to achieve involvement of the embodied self in movement induced by the physiotherapist.

Similarly, the patient's active movement when the oPT's hands-on facilitation techniques succeeded involve activation of the SO through enhanced activation of sensory integration, as described previously. However, aspects of the patient's SA will potentially also be augmented as executive networks are activated when the patient takes over and moves actively. The physical interaction through the physiotherapist's adjustments with his/her hands (or other parts of the body) is considered a source for the exchange of pre-reflective information between the patient and the physiotherapist that enables the patient to conduct movement or new patterns of movement. However, because the physiotherapist actually initiates the movement, there will be restrictions regarding how much the patient's SA is developed compared to when the patient moves independently.

The present study emphasise that PwMS' active participation is not necessarily related to whether the patient is moving independently or not. The embodied self's participation appears to occur on reflective, pre-reflective, and automatic/non-conscious levels, a process in which integration and fluctuation between the levels seem to be essential for normal action. Recognition of these different aspects and levels of participation for PwMS is of relevance in physiotherapy, as active participation is regarded as a prerequisite for motor learning (Brodal, 2010b; Carr & Shepherd, 2010; Shumway-Cook & Wollacott, 2012; Taub, 2004). Different aspects of participation will allow for the respective features to be included in the learning process and the nuances of this process to be explored.

8.2.2 Perceptions of change and sense making

The other central finding in Study I was the reported perceptions of changes in standing up/sitting down and walking following the consultation (PGIC, BRSPE). With the limitations in mind (Section 6.6 and Paper I), we concluded in the paper that these ratings may be related to the oPT's attention towards changes and the explorative treatment that aimed to improve

these factors during the sessions. These conclusions are supported by the findings in study II, where the informants described several perceived improvements in range of movement, sensibility, alignment, pain, and activity level (sitting to standing, standing balance, dressing and walking), but also aspects of decline (tiredness). Observable changes in the quality of movement were confirmed during non-participating observations in studies II and III. The perceived changes were interpreted as significant elements that deepened the patients' and the cPTs' insights into the patients' movement disturbances during ADL.

Perceptions of change in performance of movement in these settings are of relevance because there is no general agreement whether explorations of change in movement are incorporated into the assessment of people with neurological conditions, such as MS. Nor is it agreement on search for improvement during one single session of treatment. Some authors in the field (Gjelsvik, 2008; P. Johnson, 2009) include this aspect both in assessment and treatment, while others (Carr & Shepherd, 1998, 2010; De Souza & Bates, 2011; EMSP, 2004; Shumway-Cook & Wollacott, 2007, 2012) in assessment emphasise to only record factors related to body structure and functions, activities and participation in ADL. The present study document and highlight the significance of optimising improvement as integrated in assessment to enhance sense making in the situation.

In physiotherapy, the last decades have been dominated by a substantial focus on adaptation of the environment and tasks in the therapeutic settings to allow the patient to solve problems independently. This tendency may have been encouraged by the application of the Dynamical Systems Theories (Bernstein, 1967; E. J. Gibson & Walker, 1984; Hopkins & Butterworth, 1997; Thelen, 1995) to physiotherapy. A key element in these theories is the capacity of the CNS to self-organise motor control according to the task and the environment with less focus on the CNS and the body's prerequisites for organising it. Some traditions emphasise training of functional tasks, often performed in groups and incorporating elements of strength training, verbal instruction and minimal hands-on techniques (Carr & Shepherd, 1987, 1998, 2010; Taub, 2004; Winstein & Wolf, 2008). Other approaches underline the need to treat and optimise various relevant body functions and structures interchangeable with functional tasks (activities) within a single treatment session (Gjelsvik, 2008; Raine, Meadows, & Lynche-

Ellerington, 2009; Shumway-Cook & Wollacott, 2007, 2012). These authors focus more on altering the neuromuscular and biomechanical constraints as a basis for the CNS's self-organisation to perform a task with optimal quality of movement. The present study suggests that using skilled hands-on techniques may have a positive short-term impact on both body functions and activities. These findings are consistent with Pedersen's and Normann's (2012) study of single sessions of treatment of patients following a stroke. Furthermore, the results are in agreement with Øberg (2008), who describes short-term improvements in the quality of movement when the physiotherapists used their hands in a dynamic and adaptive way while treating small children born preterm. Negative changes, such as the reported temporary increase in tiredness (Study II), were followed by deterioration in walking ability. Schmith et al. (2006) report a short-term increase in sensory impairments following single sessions of strength training, but no influence on ADL. The reported changes in performance of movement in the present study are considered to provide a change in the constraints for movement within the individual's subsystems, including the CNS' networks and musculoskeletal system. These altered constraints could be an advantage or disadvantage for optimising movement. However, using dynamic systems theories for understanding these perceived changes involves a third-person perspective of the body. This comprehension will be extended by applying the framework underpinning the present study, a framework that includes first-person phenomena without excluding third-person neurological processes.

Based on the phenomenology of the body in which neurobiology is integrated, we understand the oPT's specific handling (specific mobilisation of tissue) combined with patient's active movement of the feet, for example, as an activation or updating of the patient's body schemes through mobilisation of the skin, musculature and joints via the sensory pathways. These ascending multimodal signals are integrated at different levels in the CNS and end in the cortical networks that form representations of the body, which constitute a vital neurobiological correlate for the person's SO. As representations of the body in the CNS are known to be dynamic and activity dependent (Brodal, 2010a; Levin et al., 2009; Murphy & Corbett, 2009), it is reasonable to consider that the perceived changes are related to temporary changes within these schemes and executive networks due to the dynamic and plastic reorganisation abilities of the CNS (Section 2). A fine-tuned integration of sensory and motor networks is important to improve the interplay between proximal and distal body parts that is

vital for allowing selective movement and engagement during ADL to occur. Descending ventromedial systems generate dynamic stability to adjust for the displacements produced by movements of the arms and legs. Based on continuously updated body schemes, these descending systems activate preparatory postural adjustments (pAPAs) and accompanying postural adjustments (aAPAs) while performing the activities (Brodal, 2004; Raine, 2009; Shumway-Cook & Wollacott, 2012). The update of body schemes is based on the continuous processing of information from the sensory networks, in which information from the feet and axial musculature is particularly important (Brodal, 2004; Kibler et al., 2006). The described physical interactions potentially activate some of these mechanisms. Furthermore, improvement of proximal stability is known to augment coordination and strength of movement distally (Kibler et al., 2006). It is therefore reasonable to suggest that the perceived improvement in walking in the present study may be related to recruitment of more proximal stability and enhanced integration of sensory information. The focus on core stability and the implications for balance and walking in the present study are in accordance with recent studies (Freeman et al., 2012; Freeman et al., 2010) in which improvement was detected and will be further investigated.

Merleau-Ponty's elaborations ([1962] 2008) allow for a deeper understanding of perceptions of change in movement. We understand the reported changes in adaptations to the floor, alignment, posture and walking as alterations in the entity motility, sensation and perception; these adaptations suggest that changes in the patient's embodied intentionality have occurred. Given that meaning is constructed by the patient, such changes may strengthen the to – from structure between the person and the surroundings (the intentional arch) and may optimise engagement in ADL. The oPT's facilitation techniques enabled the patient to walk more fluidly or to actively move body parts within previously inaccessible ranges; we consider these changes to impose an (intentional level) user-pressure on the pre-reflective and non-conscious aspects of movement. Based on the assumptions that postural aspects of movement are monitored primarily in subcortical networks (Brodal, 2010a), physical handling and facilitation techniques appear appropriate to address these factors. The reported perceptions of improved balance and walking in the present study are considered to strengthen or underpin the patient's SA or the feeling of being in control of one's own movements. The described decline of other factors is considered to undermine the patient's SA. Furthermore, the

temporary improvements can be seen as re-accessing aspects of the earlier habitual body or as making more options available for the present body. Moreover, the reported increased decline in walking is considered to facilitate further development of a new habitual body through augmentation of compensatory movement strategies. The professional choice between rehabilitation through facilitation of more optimal movement strategies versus compensatory solutions is discussed by Pelletier et al. (2009) and Levin et al. (2009) emphasising the need for the former. Use of compensatory strategies to achieve improvement is documented and criticised in physiotherapy to people with stroke (Kitago et al., 2012). The present study supports these authors' considerations and broadens the understanding of improvements in quality of movement by applying a first-person perspective to the body.

Perceptions of change and PwMS' insights

The finding that the perceptions of change in performance of movement were vital for the patients' insights into their own movement limitations and potentials for ADL is relevant regarding the reported need for education and information for these patients (Dawson et al., 2004; EMSP, 2012; EMSP, 2004; Solari et al., 2007). We consider that the perceived bodily changes were given conscious meaning through the dialogue with the oPT, in which the perceived changes were interlinked to what the patient described as his/her movement problems during ADL. Contextualised in this way, perceptions of change in movement may enhance sense making. These interpretations are in accordance with Gallagher's (2005) elaborations of how the body, particularly proprioception, shapes the mind. The perceived improvements seemed unexpected for the patients, and surprise has a potential for increasing reflections (Schön, 1991) and for focusing attention on the situation is vital for learning (Brodal, 2010b). The present study suggests that perceptions of change in one's own movement are a way to facilitate and achieve the necessary focused attention in the clinical setting.

These interpretations may provide explanations regarding the reported (over)fulfilment of expectations and the impact of the consultation on how subjects perceived their health problem as found in Study I (OPEQ). Previous reports have emphasised the importance for PwMS to gain insight into their own situation, especially during the initial and early phases of

MS (EMSP, 2012; Solari et al., 2007; Solari et al., 2010; Ytterberg et al., 2008); in addition, more education from physiotherapists to PwMS in hospital settings has been requested (Gillanders et al., 2006). The present study supports these attitudes, suggesting an explicit focus on body and movement is a specific integral part of sense making.

Perceptions of change and cPTs' insights

In paper III, we concluded that the joint observations of the patient's changes in performance while standing, moving between postures and walking were important for strengthening the movement analyses and clinical reasoning or the cPTs' sense making in the setting. The oPT's focus on evaluations of potential "results" or improvements in quality of movement following the explorative interventions were considered to give the cPTs access to the active elements in practice knowledge described by Schön (1991) and Molander (1996). The "results" or changes in quality of movement that evolved following the explorative treatment were reported to be essential for the professional guidance (Study III). These changes in performance seem to be what Schön (1991) terms *surprises* that facilitate reflections-in-action and -on-action. Aiming for improvement in single sessions involves evaluations during the session, could be associated with what Wainwright et al. (2010) term *self-assessment* which is less used by novice physiotherapists, and *assessment-re-assessment* described Petty et al. (2011) to enhance learning from clinical practice. As the cPTs mainly were observing while the oPT was interacting with the patient, the reflection-in-action was associated with following the oPT's actions and verbal considerations. This way of "shadowing" the oPT provided access to a clinical reasoning process in which the hypothesis of why the patient moves the way he/she does is actually investigated or tested. The significance of guidance in reflection-in-action is consistent with Wainwright et al. (2010) who reported that this is the most striking difference between novice physiotherapists and experts.

Clinical reasoning involves continuous sense making in the situation and is one of the fundamental skills for individualised physiotherapy (Dahlgren et al., 2004); therefore, this skill is vital in professional guidance. Using Schön's terms, these guidance sessions can be considered as supervision in joint problem setting through naming and framing of the patient's movement problems. As normal movement and ADL appeared to be the reference

for the oPT during this process, aspects of general character applicable to other patients became available for the cPTs. Participating in this process, in which observation of changes in performance of movement played an essential part, formed a vital basis for the cPTs to involve in the subsequent discussions or reflections-on-action. We consider these discussions to be examples of dialectical learning situations described as vital for reflective practice (Dahlgren et al., 2004, p. 32). Dialectical learning describes a concept of sense making as a co-construction; what is called ‘participatory sense-making’ by De Jaegher and Di Paolo (2007). This involves not only the transmission of knowledge, but also its transformation and extension through interplay and mutual exchange between the participants. Because the active elements in practice knowledge are context bound, professional guidance in real-life situations is appropriate for the transference and transformation of such elements of knowledge. Observations of a continuum of treatment designed for improvement may inspire an explorative and evaluative approach during assessment. Such an approach is associated with *intelligent practice* that opposes routine and *habitual practice*, as described by the philosopher Gilbert Ryle (1945). Compared to previous studies (Dowds & French, 2008; Fleet et al., 2008; Petty et al., 2011; Wainwright et al., 2010), the current study highlight the significance of body and movement as an integral and fundamental part of sense making in professional guidance.

8.2.3 Knowhow and continuity of care

Study I indicates that PwMS experienced high satisfaction regarding guidance in self-assisted exercises and with the oPT’s professional skills (OPEQ). These results were supported and further described through the findings from study II. The regular single sessions for PwMS in the OP clinic held an ambition of giving ideas of subsequent performance of self-assisted activities or training. Similarly, the professional guidance sessions for the cPTs aimed to inform subsequent treatments of the patient. Both studies indicated that this information may influence subsequent activities to a degree that is dependent on several aspects.

Self-assisted exercises

Advice regarding what the patients can do on their own to maintain or improve functional activities in daily life was emphasised by the informants as an essential element in the

consultation (study II), and this finding is in accordance with other reports (EMSP,2012; Gillanders et al., 2006). The results from study II indicated that the less disabled patients believed they would be able to perform some of the suggested exercises, while the more disabled patients did not. This variation is reasonable, as people with mild dysfunctions most likely have better sensorimotor control in their movements compared to people suffering from moderate to severe MS. However, even for PwMS with minor deviations from normal gait and balance as is the case in the early phases of MS, one session of guidance may not be sufficient to perform the exercises in a way that activates new strategies as opposed to already established compensatory strategies. Given that home exercises aim to impose user-pressure to improve the quality of movements, such as coordination and flexibility; based on theories of neuroplasticity, it is essential that the activities are performed in a way that enhances the quality of these movements. The current study emphasises the need for specificity in movement analysis to understand what specific aspects of a movement (e.g., balance and walking) the patient will benefit from improving and the need to incorporate these aspects into the self-assisted exercises.

Knowledge of *what* to do and *how* to conduct the specific activities and *why* the activities are beneficial are requirements for performing self-assisted exercises in an optimal way. These factors are particularly challenging for PwMS, as they have impaired sensorimotor control and an adapted habitual body, which impacts what independently conducted exercises the present body is able to perform and to what degree. The distinction provided by Ryle (1945) between *knowing how* and *knowing that* may illuminate some aspects regarding these challenges. The first term refers to skills and capacities to conduct certain actions, and the second term refers to knowing how things are.

In the present study, instruction on the performance of these exercises was conducted through hands-on facilitation accompanied by verbal instructions. This interaction provided some idea of what the exercises were and how to perform them. Furthermore, implementation of the movements, which in the session were associated with subsequent improvement in the performance of balance or walking, augmented the relevance of the exercises for the patients. The engagement shown by the patients regarding implementation of these activities into the home-program may be due to “revisiting” former aspects of being in control of one’s movement or an enhanced feeling of SA that augmented the motivation to perform the

particular exercises. Integration of physical handling and verbal instruction or addressing the embodied self through both reflective and pre-reflective approaches seems to be an essential contextualisation for the introduction of home-exercises in addition to perceived improvements. We suggest that these aspects deepen the patients' insights into what the exercises are and why they are beneficial, and associate this information with their *knowing that*. However, it is uncertain whether and to what degree the patients were classified as *knowing how* to perform them on their own at home in the subsequent period.

These considerations are relevant regarding how to individualise both self-assisted exercises and strength and fitness-training and timing of admission to physiotherapy. So far, the focus in strength and fitness training has been more on dose and intensity (Dalgas et al., 2009; EMSP, 2012) than on quality of movement, and recommendations for physiotherapy has been associated with moderate disability more than initial phase/minor disability. The present study directs focus to the significance of individualisation, guidance through body and movement and the need for follow-up to acquire the necessary skills to perform self-assisted exercises and self-management. These considerations are relevant with regard to the reported need for health promotion for PwMS (Kasser & Kosma, 2012) and coping strategies including physical activity (Lode et al., 2010; Lode et al., 2007; Plow, Resnik, et al., 2009).

Subsequent treatment

The guidance sessions for the cPTs similarly aimed to develop their professional competency and to enhance the quality and continuity of care, which is a key element to enhance quality in health care (Helse- og omsorgstjenesteloven, 2011). However, there may be a "gap" between participating in a detailed movement analyses or in verbalised reflections-in-actions and -on-actions with an expert physiotherapist and doing similar analyses alone, even with the same patient and particularly with a different patient. Based on the need for varied repetition in learning processes, it is reasonable that particularly the less experienced cPTs reported challenges in terms of implementing the clinical training during subsequent treatment sessions with the patient. The reservoir of experiences of these cPTs, to use Schön (1991) term, may have been too small or too deviant from what the oPT performed in the clinical guidance session. Hence, the cPTs were unable to integrate the advice with their previously incorporated knowledge, particularly regarding handling techniques. The more experienced

cPTs reported having the ability to apply the advice to subsequent treatments of the patient in question and to similar patients. Hence, a certain degree of previous practice knowledge appeared to be necessary.

We suggest that practice from analysing movement in people with a normal CNS and people with lesions in CNS are equal important to develop the reservoir of knowledge that provide a basis for immediate identification of what aspects of an activity (e.g., balance or walking) that are problematic. This is a process associated with Grimen's (2008) identifications of gestalts and Edwards et al. (2004) term *pattern recognition*; which is a quick method of movement analysis used by expert physiotherapists. Pattern recognition in clinical reasoning are dependent upon the clinical gaze (intuition) and professional reflections in which theoretical and practical knowledge regarding human movement are integrated (Dahlgren et al., 2004). Single sessions of guidance dominated by observation, as in the current study appear to enhance the development of movement analysis aspects and pattern recognition more than skills in explorative treatment.

The cPTs, and particularly the less experienced ones, described the handling performed by the oPT as difficult to replicate on their own. However, the more experienced cPTs appeared to focus on the principles and indicated that the session had provided them with ideas and actions to explore and adapt in subsequent treatments. The skills that enabled the cPTs to transfer the information to subsequent treatments, in accordance with Schön (1991) and Molander (1996), were based on incorporated knowledge from doing similar actions. Because the cPTs only sporadically performed the handling under supervision during the sessions, the skill development for the less experienced cPTs was compromised. The handling skills for the facilitation of movement contain integrated and timed elements of touch, compression, traction and indicating a direction, such as an invitation to move (Gjelsvik, 2008). Such physical interactions involve elements that are consistent with Grimes' (2008) terms choreography of movement, which are skills difficult to transfer to others through words; and even demonstrations are insufficient because the skills involve fine-tuned physical interactions that need to be felt rather than observed.

Practical skills need adapted arenas for transference and expansion (Grimen, 2008); it is insufficient to have these skills only demonstrated, which illuminates the challenges in using authentic clinical settings as arenas for supervision. The ultimate demand in such settings is to care for the patient, and that implies second priority for the physiotherapist who undergoes professional guidance (Ernstzen et al., 2009). It may be unfavourable if the oPT and the cPT are interchangeably handling the patient during the same session, particularly when the learner is less skilled in the handling. This situation may minimise the chance of the patient achieving improvements in quality of movement, which are emphasised as fundamental both for the patients' and for the cPTs' sense making and development of knowledge. These considerations are in accordance with the cPTs' reported need for other arenas to practice basic handling skills in movement analyses and exploration of changes (e.g., at professional networks and seminars with colleagues). In such situations, various handling techniques could be practiced on other cPTs under the supervision of an expert practitioner. Practicing handling skills to optimise the quality of movement on other cPTs provides embodied experiences regarding both how to perform the techniques and how to establish a physical "dialogue" with the other individual through the hands.

Structural elements

Information sharing between the OP clinic and particularly the oPT and cPT was requested. In our study, the cPTs received a written report of the oPT's assessment. To obtain its purpose of informing the cPT in the community, the cPTs reported a need for using plain language. Jargon and extensive details were described by the less experienced cPTs as being difficult to understand. Adjusting the language and terms to the receiver is essential for all communication, such as the collaborations among health care levels. However, the cPTs reported a greater understanding of the report after participating in the guidance session, which indicates that guidance in clinical settings may positively influence the verbal exchange of information.

No protocols describing how the cPTs should report to the hospital prior to their patient's consultation, were found. The cPTs described a need to participate in the decision of both when they need professional guidance and for which patients. The regular appointment at the

OP clinic did not necessarily coincide with when the cPTs struggle to achieve maintenance or improvement in the treatment of their patients. These results, which are in accordance with the request in political documents (Helse- og omsorgstjenesteloven, 2011) and guidelines (EMSP, 2012; Helse Nord, 2007; NICE, 2004), suggest enhanced development of mutual information routines between health care levels is needed as concerns PwMS. The present study indicates a need for greater emphasis on the primary health care perspective (the cPTs) in the collaboration between the two health care levels.

The need for early admittance to physiotherapy for both information and treatment was indicated in the current study (Study II and III). The former is consistent with recommendations regarding needs for tailored information (EMSP, 2012; EMSP, 2007; Solari et al., 2010). As the body and movement appear to have a significant impact on what is understood from the verbal information, procedures regarding admission to physiotherapy in the OP clinic should be considered when the diagnosis is established. Additionally, based on the danger of relearning compensatory strategies and the opportunity to perform self-assisted exercises, procedures for admission to neurological physiotherapy including treatment in the early phases and following any exacerbations should be considered.

Continuity and quality of care are a focus in health care today, especially for patients with chronic diseases, such as PwMS and professional competency is a fundamental aspect for achieving this (EMSP, 2012; Guthrie et al., 2008; Helse- og omsorgstjenesteloven, 2011). Neurological physiotherapy is one of the specialities in the profession that is rarely represented in community health care (NFF, 2012a). There are many reasons for the lack of this type of competency. First, many Norwegian municipalities are small, and therefore the cPTs must treat people with a variety of diseases; so far, there has been less economic gain from being a specialist in neurological physiotherapy in private practice in the communities. The current study supports the need for each municipality to consider whether competent neurological physiotherapy is available; this recommendation is in line with the Norwegian authorities' (Helse-og omsorgsdepartementet [HOD], 2011) focus on neuro-rehabilitation in primary health care. Furthermore, professional guidance in OP clinics may be a relevant

setting to be more systematically incorporated in broader CPD programs; allowing more emphasis on development of the active elements in practice knowledge.

8.3 Conclusions

8.3.1 Integrated perspectives as a foundation for neurological physiotherapy

This thesis provides an incipient exploration of a theoretical foundation for neurological physiotherapy that extends the traditional biomedical perspective. The use of phenomenology of the body as an overall theoretical basis enables a conception of the body as the centre for expression and experience that includes both pre-reflective and reflective levels. These concepts allow for an understanding of the physical interaction between the physiotherapist and the patient as a form of communication similar to verbal and non-verbal communication (gesticulations, etc.), which expands the comprehension of physical handling or interaction in physiotherapy. The phenomenological ambiguousness of the body, simultaneously being and having a body or simultaneously a body-as-subject and a body-as-object, integrates relevant neurobiology and muscular and movement sciences and the possibility of complementing these approaches with practice knowledge. The integration of these perspectives appears to generate new ways of understanding movement disturbances in PwMS, professional actions of the physiotherapist and the interactions between the two. It seems that more aspects of the complexity in clinical physiotherapy encounters and particularly the inter-subjective process are anchored in theory when applying the named overall perspective integrated with theory from the other traditions. However, this theoretical platform still needs to be elaborated and deepened as concerns neurological physiotherapy.

8.3.2 The main insights derived from the analysis

Regular single sessions of physiotherapy in OP clinics that include systematic and individualised assessment and explorative treatment designed to improve the quality of movement, integrated with educational elements and guidance in self-assisted exercises address a need in PwMS from the initial phase and throughout the course of the disease. High satisfaction with such single sessions was found, and both relational and content factors and

collaboration between the speciality health care and the primary health care physiotherapists may contribute to this result.

Participation through body and movement plays an essential role in the inter-subjective process between the physiotherapist and PwMS. Expressions and experiences through movement and physical interactions (handling), in which verbal communication is embedded, bring forward a nuanced and enriched information flow when joint attention between the two is obtained. The perceptions of movement seem to be significant for deepening the communication process, allowing pre-reflective information to be exchanged and integrated in reflective considerations regarding how the movement disturbances influence ADL.

Perceptions of change in body functions and performance of activities may occur following single sessions of assessment and explorative treatment for PwMS. Such improvements in performance of movement are understood as a change in intentionality, and an enhancement of the patient's SO and SA, and hence a potential change in their ability to engage in ADL. Perceptions of change in movement appeared as a strong element in PwMS' sense-making process and deepened their insights when the specific movement experiences were contextualised in the oPT's explanations, in which the changes were interlinked with basic elements of relevant ADL.

PwMS reported guidance and follow-up in self-assisted exercises to be important. Hands-on guidance appeared to be a vital element in instruction to enable the patient to actively perform exercises that explore new and more optimal movement strategies. Implementation of movements that the patient experienced led to improvement in the particular setting appeared to augment the relevance of the particular exercise for the patient. Sensory motor control of movement, which often is more available in the early phases of MS, seem to be essential for subsequent performance of such home programs. However, less is known with regard to the implementation of these self-assisted activities subsequently on their own.

Participation in authentic movement analysis of a familiar patient in which hands-on facilitation techniques were used seemed to augment development of active elements in practice knowledge and particularly cPTs' clinical reasoning skills. Changes that evolved during explorative treatment in clinical guidance sessions seemed to strengthen and deepen the cPTs' sense making in the particular situation and the relevance of treatment for similar patients. These perceived changes provided directions for possibilities in subsequent treatments and reinforced reflections in practice and on practice. Observing how improvement in movement (or decline) is accomplished through the interaction between the oPT and the patient provides access to vital context bound elements in practice knowledge only available through first-hand experience.

Professional guidance through observing an expert physiotherapist assess and treat a patient with MS seems insufficient with regard to the development of handling skills. Previous practice knowledge regarding neurological physiotherapy seem to determine what the cPTs gain from the guidance session concerning the implementation of the advice in subsequent treatment.

Complementary ways of learning involving supervision of the cPTs' actions seem necessary. Strengthening of the cPTs' perspectives as a basis for professional guidance and as structures and language for mutual collaboration is requested.

8.4 Implications for practice and further research

The present study highlights the significance of a systematic and individualised therapeutic approach, characterised by the integration of assessment, exploration of possibilities for improvement, information, and further guidance in single sessions of physiotherapy in OP clinics for PwMS. The significance of body and movement in the inter-subjective process calls for the consideration of such a physiotherapy approach when information and counselling programs for PwMS are discussed and when protocols involving the access and timing of physiotherapy are evaluated.

Using authentic clinical settings of assessment and explorative treatment in the hospitals' OP clinics for PwMS as an arena for clinical guidance of cPTs allow aspects of knowledge unavailable in other ways to be transferred and developed, and such settings should be considered when planning CPD programs designed to develop competency in neurological physiotherapy for cPTs and when discussing collaborations between health care levels.

The present study was small and should be complemented with future similar studies that address the limitations of the present study. Continuity of care is a vital scope for future research; in particular, the link between the initial physiotherapy service at the OP clinic and the community-based physiotherapy service in a long-term perspective needs to be investigated. Within this scope, CPD, follow-up in the performance of self-assisting exercises and the effect of intensive specific and individualised interventions designed to improve quality of movement should be investigated. Finally, a further deepening of the concept of embodiment as a theoretical foundation for neurological physiotherapy is necessary to develop physiotherapy-specific terms in which this understanding is embedded.

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Papers I-III

Paper I

Normann B, Moe S, Salvesen R, Sørgaard KW: *Patient satisfaction and perception of change following single physiotherapy consultations in a hospital's outpatient clinic for people with multiple sclerosis*. *Physiotherapy Theory and Practice*, 2011, Early Online, 1–11 Copyright © Informa Healthcare USA, Inc. ISSN: 0959-3985 print/1532-5040 online DOI: 10.3109/09593985.2011.574782

Paper II

Normann B, Sørgaard KW, Salvesen R, Moe S: *Contextualized perceptions of movement as a source of expanded insight: People with multiple sclerosis' experience with physiotherapy*. *Physiotherapy Theory and Practice*, Early Online: 1–12, 2012 Copyright © Informa Healthcare USA, Inc. ISSN: 0959-3985 print/1532-5040 online DOI: 10.3109/09593985.2012.698717

Paper III

Normann B, Sørgaard KW, Salvesen R, Moe S: *Clinical guidance for community physiotherapists treating people with MS: Professional development and continuity of care.*

Submitted to Physiotherapy Research International, in review.

Appendices

1. Approval from the Regional Committee for Medical and Health Research Ethics
2. Approval from the Norwegian Social Science Data Services
3. Informed consent, patients
4. Informed consent, community physiotherapists
5. Outpatient Experience Questionnaire (OPEQ)
6. Patient Global Impression of Change (PGIC)
7. Borg's Rating Scale of Perceived Exertion (BRSPE)
8. Observational guide, patients
9. Observational guide, community physiotherapists
10. Interview guide, patients
11. Interview guide, community physiotherapists (cPTs)
12. Overview of the final analyses (results from papers I, II, III)

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**P REK NORD 65/2006 UTVIKLING OG DOKUMENTASJON AV NYTT
FYSIOTERAPITILBUD FOR MS-PASIENTER - SLUTTAVURDERING - KOMITEEN
HAR INGEN INNVENDINGER MOT AT PROSJEKTET GJENNOMFØRES**

Vi viser til prosjektleders brev av 12.7.2006 og revidert forespørsel om deltakelse i forskningsprosjektet innsendt som vedlegg til e-post 20.7.2006.

Prosjektleders tilbakemelding på komiteens merknader til prosjektet i møtet 15.6.2006 (brev av 23.6.2006) tas til etterretning.

Regional komité for medisinsk forskningsetikk, Nord-Norge (REK Nord) har ingen innvendinger mot at prosjektet gjennomføres.

Det forutsettes at prosjektet er godkjent av aktuelle formelle instanser før det settes i gang.

Det forutsettes at prosjektet forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger som komiteen har basert sin avgjørelse på.

Komiteen ber om å få melding dersom prosjektet ikke blir slutført.

Vennlig hilsen



Ingunn Ytrehus
førstekonsulent

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TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 19.07.2006. Meldingen gjelder prosjektet:

15105	<i>Utvikling og dokumentasjon av nytt fysioterapitilbud til pasienter med multipel sklerose</i>
Behandlingsansvarlig	<i>Nordlandssykehuset HF, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Britt Normann</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldingen, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/endingsskjema>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

¹⁾ Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/register/>

Personvernombudet vil ved prosjektets avslutning, 30.08.2007 rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

for
Bjørn Ikenrichsen

Atle Alvsheim

for Teigland
Geir Teigland

Kontaktperson: Geir Teigland tlf: 55 58 33 48

Vedlegg: Prosjektvurdering

Personvernombudet for forskning, NSD



Prosjektvurdering - Kommentar

15105

Personvernombudet forutsetter at datamaterialet anonymiseres ved prosjektslutt 30.08.2007. Videre oppbevaring og bruk av videoopptak utover prosjektet forutsetter pasientenes samtykke og melding til Datatilsynet.

Prosjektet forutsettes tilrådd av Regional komité for medisinsk forskningsetikk før prosjektstart, ombudet ber om at kopi av tilrådning oversendes når den foreligger.

Appendix 3

Forespørsel om å delta i forskningsprosjektet: ”Utvikling og dokumentasjon av nytt fysioterapitilbud til pasienter med Multippel Sklerose”.

Innledning

Nevrologisk avdeling ved Nordlandssykehuset har i flere år drevet MS-poliklinikk med lege og sykepleier, og sporadisk har fysioterapi vært inkludert. Seksjon for ergo- og fysioterapi og Nevrologisk avdeling starter nå et forskningsprosjekt hvor fysioterapi inngår i dette tilbudet. Dette informasjonsskrivet gir en oversikt over hva prosjektet innebærer. Når du har lest det kan du bruke inntil en uke på å avgjøre om du vil delta – diskuter det gjerne med familie, venner eller fagfolk.

Formålet med prosjektet

Formålet er å utvikle spesialisert fysioterapi som en del av tilbudet pasientene får ved MS-poliklinikken ved Nevrologisk avdeling, NLSH. Det er sentralt å få kunnskap om pasientenes og fysioterapeutenes erfaringer med dette tilbudet. Videre er kunnskapsoverføring fra sykehuset til kommunehelsetjenesten vesentlig i prosjektet. Tilbudet retter seg dels mot den enkelte pasient og dels mot den lokale fysioterapeuten i form av veiledning. En søker å rekruttere ca.100 pasienter, og for ca.50 – som bor i Bodø/Salten og Mo i Rana-området vil det bli gjennomført praktisk veiledning til lokale fysioterapeuter. Prosjektet varer fra 01.09.06 til 01.07.07.

Metoder som skal benyttes

I undersøkelsen benyttes spørreskjema til alle pasientene. I tillegg intervjues og videofilmes et mindre utvalg av pasientene som velges ut fra grad av bevegelsesproblemer og bosted. Intervjuene tas opp på lydbånd.

Kriterier for og konsekvenser for deltakelse

For å kunne delta i prosjektet må du ha MS. Dersom du ikke ønsker å delta i prosjektet, vil du få din ordinære oppfølging og behandling av lege og sykepleier ved MS-poliklinikken som før.

Praktiske følger av deltakelse

Dersom du samtykker i å delta i prosjektet, vil du få time hos spesialfysioterapeuten, fortrinnsvis samme dag som du skal til lege og sykepleier ved MS-poliklinikken. Hun vil foreta undersøkelse og funksjonsvurdering av deg samt gi deg praktiske råd når det gjelder egentrening. I forbindelse med undersøkelsen vil fysioterapeuten ta opp video/bilder av hvordan du sitter, eventuelt reiser deg og går. Dette materialet blir forsvarlig oppbevart ved sykehuset. Videre vil fysioterapeuten utføre tester av balanse og gange. Fysioterapeuten sender rapport med veiledning i videre behandling til din lokale fysioterapeut.

Etter konsultasjonen hos fysioterapeuten på poliklinikken ber vi deg om å svare på spørreskjema. Senere vil du bli bedt om å svare på i hvilken grad du opplever endringer i fysioterapitilbudet lokalt. Innen 3 uker etter konsultasjonen hos fysioterapeuten på MS-poliklinikken gjennomføres praktisk veiledning for ca. halvparten av pasientene. Da møtes

pasient, lokal fysioterapeut og spesialfysioterapeuten enten på sykehuset eller hos din lokale fysioterapeut.

For et utvalg pasienter vil konsultasjonen hos fysioterapeuten på MS-poliklinikken og veiledningen med den lokale fysioterapeuten bli filmet og brukes som bakgrunn for intervju. Filming og intervju gjennomføres av fysioterapeut Britt Normann.

Fordeler ved å delta i prosjektet

Du vil få en grundig undersøkelse og konkrete råd i forhold til hva du kan gjøre selv for å opprettholde og eventuelt bedre din funksjon av en fysioterapeut med spesialkompetanse innen nevrologisk fysioterapi. Det er ingen ekstra utgifter forbundet med å delta. Videreformidling av informasjon og kompetanse til din lokale fysioterapeut håper vi kan bidra til å bedre tilbudet og på den måten være positivt for din situasjon videre.

Konfidensialitet.

Alle personer med tilknytning til prosjektet har taushetsplikt. Det er kun opplysninger som er nødvendige for prosjektet som blir samlet inn. Alle data som benyttes vil bli avidentifisert og forsvarlig oppbevart. Hvis resultatene offentliggjøres, vil identiteten din ikke kunne gjenkjennes. Alle lydbåndopptak vil bli forsvarlig oppbevart og slettet ved prosjektets slutt. Videoopptak av hele konsultasjoner, som gjøres på et mindre antall pasienter, oppbevares forsvarlig for videre innholdsanalyse som skal inngå i en videre studie som er under planlegging. Etter innholdsanalyse ber en om lov til å oppbevare materialet for å kunne bruke avidentifiserte utdrag av videomaterialet i undervisnings- og foredragsvirksomhet senere.

Det understrekes at det er helt frivillig å delta i prosjektet og at du når som helst kan trekke deg og få alle tidligere registrerte opplysninger slettet uten å oppgi noen grunn. Dette vil ikke ha noen innvirkning på din fremtidige oppfølging fra sykehuset.

Denne forespørselen sendes ut med to informasjonsskriv med samtykkeerklæring. Dersom du ønsker å delta i forskningsprosjektet, krysser du av for de delene du samtykker til og returnerer et signert eksemplar i vedlagte frankerte svarconvolutt. Det andre beholder du som kopi. Du vil så bli kontaktet for time hos fysioterapeut på MS-poliklinikken.

Prosjektet er meldt til Personvernombudet for forskning, tilrådd av Regional komité for forskning og finansiert av Fond for etter og videreutdanning av fysioterapeuter. Dersom det er noe du ikke helt forstår er du velkommen til å ta kontakt med prosjektleder Britt Normann tlf.755 34530/99614941, E-post: Britt.Normann@nlsh.no

SAMTYKKEERKLÆRING

Jeg har lest informasjonen om forskningsprosjektet "Utvikling og dokumentasjon av nytt fysioterapitilbud til pasienter med Multippel Sklerose".

Jeg samtykker i å delta i prosjektet og har nedenfor krysset av for det jeg samtykker til:

Utfylling av spørreskjemaer ()
Videofilming og intervju ()
Bruk av videomateriale i undervisning ()

Signatur (pasient)

Dato (oppgitt av pasienten)

Appendix 4

Forespørsel om å delta i forskningsprosjektet: ”Utvikling og dokumentasjon av nytt fysioterapitilbud til pasienter med Multippel Sklerose”.

Innledning

Nevrologisk avdeling ved Nordlandssykehuset har i flere år drevet MS-poliklinikk med lege og sykepleier, og sporadisk har fysioterapi vært inkludert. Seksjon for ergo- og fysioterapi og Nevrologisk avdeling starter nå et forskningsprosjekt hvor fysioterapi inngår i dette tilbudet. Dette informasjonsskrivet gir en oversikt over hva prosjektet innebærer.

Formålet med prosjektet

Formålet er å utvikle spesialisert fysioterapi som en del av tilbudet pasientene får ved MS-poliklinikken ved Nevrologisk avdeling, NLSH. Det er sentralt å få kunnskap om pasientenes og fysioterapeutenes erfaringer med dette tilbudet. Videre er kunnskapsoverføring fra sykehuset til kommunehelsetjenesten vesentlig i prosjektet. Tilbudet retter seg dels mot den enkelte pasient og dels mot den lokale fysioterapeuten i form av veiledning. En søker å rekruttere ca.100 pasienter, og for ca.50 – som bor i Bodø/Salten og Mo i Rana-området vil det bli gjennomført praktisk veiledning til lokale fysioterapeuter. Prosjektet varer fra 01.09.06 til 01.07.07.

Metoder som skal benyttes

I undersøkelsen benyttes spørreskjema til alle pasientene. I tillegg intervjues og videofilmes et mindre utvalg av pasientene som velges ut fra grad av bevegelsesproblemer og bosted. Videre intervjues en del av fysioterapeutene som har fått veiledning. Intervjuene tas opp på lydbånd.

Kriterier for og konsekvenser for deltakelse

For å kunne delta i prosjektet må pasienten ha MS. Dersom vedkommende ikke ønsker å delta i prosjektet, får han /hun sin ordinære oppfølging og behandling av lege og sykepleier ved MS-poliklinikken som før.

Praktiske følger av deltakelse

Pasientene som deltar i prosjektet, får time hos spesialfysioterapeuten på poliklinikken, fortrinnsvis samme dag som timen hos lege og sykepleier ved MS-poliklinikken. Hun vil foreta undersøkelse og funksjonsvurdering av pasienten samt gi praktiske råd når det gjelder egentrening. I forbindelse med undersøkelsen vil fysioterapeuten ta opp video/bilder av hvordan pasienten sitter, eventuelt reiser deg og går. Dette materialet blir forsvarlig oppbevart ved sykehuset. Videre vil fysioterapeuten utføre tester av balanse og gange. Fysioterapeuten sender rapport med veiledning i videre behandling til den lokale fysioterapeut.

Etter konsultasjonen hos fysioterapeuten på poliklinikken ber vi pasienten om å svare på spørreskjema. Innen 3 uker etter konsultasjonen hos fysioterapeuten på MS- poliklinikken gjennomføres praktisk veiledning for ca. halvparten av pasientene. Da møtes pasient, lokal fysioterapeut og spesialfysioterapeuten enten på sykehuset eller hos den lokale fysioterapeuten. Senere vil pasienten bli bedt om å svare på om/i hvilken grad vedkommende opplever endringer i fysioterapitilbudet lokalt.

For et utvalg pasienter vil konsultasjonen hos fysioterapeuten på MS-poliklinikken og veiledningen med den lokale fysioterapeuten bli filmet og brukes som bakgrunn for intervju.

Filming og intervju gjennomføres av fysioterapeut Britt Normann.

Fordeler ved å delta i prosjektet

Pasienten vil få en grundig undersøkelse og konkrete råd i forhold til hva en kan gjøre selv for å opprettholde og eventuelt bedre sin funksjon av en fysioterapeut med spesialkompetanse innen nevrologisk fysioterapi. Pasienten har ingen ekstra utgifter forbundet med å delta. Den praktiske veiledningen dekkes inn for den lokale fysioterapeut gjennom takstplakaten. Videreformidling av informasjon og kompetanse til den lokale fysioterapeut håper vi kan bidra til å videreutvikle tilbudet og på den måten være positivt for pasientens situasjon videre.

Konfidensialitet.

Alle personer med tilknytning til prosjektet har taushetsplikt. Det er kun opplysninger som er nødvendige for prosjektet som blir samlet inn. Alle data som benyttes vil bli aidentifisert og forsvarlig oppbevart. Hvis resultatene offentliggjøres, vil identiteten din ikke kunne gjenkjennes. Ved prosjektets slutt anonymiseres alle spørreskjema for videre oppbevaring og lydbandopptak slettes. Utskrift av intervjuene og videoopptak av hele konsultasjoner, som gjøres på et mindre antall pasienter, oppbevares forsvarlig for videre innholdsanalyse som skal inngå i en videre studie som er under planlegging. Etter innholdsanalyse ber en om lov til å oppbevare materialet for å kunne bruke aidentifiserte utdrag av videomaterialet i undervisnings- og foredragsvirksomhet senere.

Det understrekes at det er helt frivillig å delta i prosjektet – både for pasient og lokal fysioterapeut – og at du når som helst kan trekke deg og få alle tidligere registrerte opplysninger slettet uten å oppgi noen grunn. Dette vil ikke ha noen innvirkning på din fremtidige oppfølging fra sykehuset.

Denne forespørselen sendes ut med to informasjonsskriv med samtykkeerklæring. Dersom du ønsker å delta i forskningsprosjektet, krysser du av for de delene du samtykker til og returnerer et signert eksemplar i vedlagte frankerte svarkonvolutt. Det andre beholder du som kopi. Du vil så bli kontaktet for veiledning av fysioterapeut på MS-poliklinikken.

Prosjektet er meldt til Personvernombudet for forskning, tilrådd av Regional komité for forskning og finansiert av Fond til etter og videreutdanning av fysioterapeuter. Dersom det er noe du ikke helt forstår er du velkommen til å ta kontakt med prosjektleder Britt Normann tlf.755 34530/99614941, E-post: britt.normann@nlsh.no

SAMTYKKEERKLÆRING

Jeg har lest informasjonen om forskningsprosjektet "Utvikling og dokumentasjon av nytt fysioterapitilbud til pasienter med Multippel Sklerose".

Jeg samtykker i å delta i prosjektet i forhold til MS-pasienter som jeg har i behandling, og har nedenfor krysset av for det jeg samtykker til:

- Klinisk veiledning
- Videofilming av klinisk veiledning
- Bruk av videomaterialet i undervisning
- Intervju

Signatur (fysioterapeut)Dato (oppgitt av fysioterapeuten).....



Undersøkelse om pasienters erfaringer med fysioterapi i MS-poliklinikk

”Det er den som har skoen på som vet hvor den trykker”. Derfor spør vi deg som har erfaring med poliklinikk eller

Spørsmålene gjelder ditt siste besøk på poliklinikken. Alles erfaringer er like viktige for å få et riktig bilde av denne delen av helsetjenesten.

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Informasjon om utfylling av spørreskjema:

- De fleste spørsmål besvares ved å krysse av på en skala med ti trinn
- Legg merke til at endepunktene er forskjellige fra spørsmål til spørsmål
- Legg også merke til at noen ganger er de positive endepunktene til venstre, andre ganger er de til høyre.

Ikke særlig tilfreds

	X								
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 Absolutt tilfreds

Utfylt skjema sendes tilbake til Nordlandssykehuset, helst i løpet av en uke.

Returkonvolutten er ferdig adressert og porto betales av Nordlandssykehuset. Alle svar blir behandlet fortrolig.

Hvis du vil kontakte Nordlandssykehuset, kan du ringe prosjektleder Britt Normann, tlf. 75 53 45 30 / 99 61 49 41.

Før du kom til poliklinikken

1. Var det lett for deg å endre tidspunktet for avtalen hvis du måtte det? Ikke aktuelt Ja Nei

2. Opplevde du at timeavtalen din ble utsatt eller flyttet uten at du ba om det? Ikke aktuelt Ja Nei

3. Hvor lang tid gikk det fra du fikk beskjed om at timen var nødvendig til du faktisk møtte til time?

Jeg møtte til time samme dag	Under 2 uker	Ca 2-4 uker	Ca 1-3 mnd	Ca 4-6 mnd	Ca 7-12 mnd	Mer enn 1 år	Husker ikke
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Hvis du måtte vente på timen din, hvordan opplevde du det?

Jeg ventet ikke Akseptabelt Uakseptabelt

5. Fikk du den informasjonen du trengte fra poliklinikken før timen din?

Jeg trengte ikke informasjon Jeg fikk nok informasjon på forhånd Jeg fikk ingen informasjon på forhånd

6. Hvor lett eller vanskelig har det vært å komme i kontakt med poliklinikkens ansatte på telefonen?

Jeg har ikke forsøkt å ringe Svært vanskelig Veldig lett

7. På forhånd, hvor viktig ventet du at denne timen på poliklinikken skulle være?

Jeg vet ikke Ikke viktig Veldig viktig

Tilgjengelighet og mottakelse på poliklinikken

8. Hvor lang tid brukte du hjemmefra til poliklinikken?

Under 1 time

Ca 1-2 timer

Ca 3-4 timer

Ca 5-8 timer

Mer enn 8 timer

9. Måtte du overnatte på grunn av reiseveien?

Ja

Nei

10. Hvordan kom du til poliklinikken? (her kan du sette flere kryss)

Privatbil

Drosje

Buss

Tog

Ferge

Fly

Annet

11. Hvor fornøyd var du med parkeringsmulighetene?

Ikke aktuelt for meg

Svært misfornøyd

Veldig fornøyd

12. Hvor lett var det å finne veien til poliklinikken da du ankom sykehuset?

Svært vanskelig

Veldig lett

13. Hvor lett var det å finne fram til MS-fysioterapeuten?

Svært vanskelig

Veldig lett

14. Hvordan ble du mottatt i fysioterapiavdelingens resepsjon?

Mottakelsen var
svært vennlig

Mottakelsen var
lite vennlig

15. Kom du inn til avtalt tid, eller måtte du vente?

Jeg kom inn til
avtalt tid

Jeg ventet mindre enn
15 minutter

Jeg ventet 15
til 30 minutter

Jeg ventet mellom
30 minutter og 1 time

Jeg ventet mer
enn 1 time

Organisering av poliklinikken

16. Opplevde du at viktig informasjon om deg var kommet fram til fysioterapeuten på poliklinikken?

Viktig informasjon manglet All viktig informasjon var tilgjengelig

17. Opplevde du at personalet på poliklinikken samarbeidet godt i forbindelse med timen din?

Nei, de samarbeidet ikke godt Ja, de samarbeidet veldig godt

18. Dersom du gjennomførte tester eller prøver, var dette godt tilrettelagt i forhold til resten av timen din?

Ikke aktuelt Ja, det var godt organisert Nei, det var ikke godt organisert

19. Var det satt av nok tid til samtale under konsultasjonen?

Ikke aktuelt Nei, det var dårlig tid Ja, det var god tid

20. Hvilket inntrykk fikk du av organiseringen av arbeidet på poliklinikken i alminnelighet?

Arbeidet virket rotete og tilfeldig Arbeidet virket meget godt organisert

21. Fikk du time hos en som du har vært hos tidligere?

Jeg hadde ikke vært der før Ja, jeg har vært hos den samme før Nei, jeg var hos en ny person

Om selve konsultasjonen på poliklinikken

22. Hvem hadde du time hos da du besøkte poliklinikken/ dagavdelingen?

Lege

Jordmor

Fysioterapeut

Sykepleier

Ernæringsfysiolog

Vet ikke

Annet

Ha fysioterapeuten i tankene når du svarer på spørsmål nr. 23 til 28:

23. Var vedkommende godt forberedt på ditt aktuelle besøk?

Vedkommende var
svært godt forberedt

Vedkommende var
ikke forberedt

24. Snakket denne personen til deg slik at du forstod ham / henne?

Han/hun var
vanskelig å forstå

Han/hun var svært
enkel å forstå

25. Hadde du tillit til at denne personen var faglig dyktig, eller følte du noen usikkerhet med hensyn til dette?

Jeg var noe usikker
på om denne personen
var faglig dyktig

Jeg hadde fullkommen
tillit til at denne personen
var faglig dyktig

26. Følte du at han eller hun hadde omsorg for deg?

Nei, ikke i det
hele tatt

Ja, i svært
stor grad

27. Fikk du selv fortalt alt det som var viktig om din tilstand?

Det var mye jeg
ikke fikk fortalt

Jeg fikk
fortalt alt

28. Ble det gjort klart for deg hva du skulle gjøre av egentrening i etterkant av timen?

Ikke aktuelt

Nei, jeg fikk ikke
vite noe om dette

Ja, jeg fikk vite
alt jeg trengte

29. Fikk du vite det du syntes var nødvendig om hvordan undersøkelsen skulle foregå?

Nei, jeg fikk ikke vite noe Ja, jeg fikk vite alt jeg trengte

30. Har du fått vite det du syntes var nødvendig om resultatet av undersøkelsen?

Nei, jeg har ikke fått vite noe Ja, jeg har fått vite alt jeg trengte

31. Fikk du vite det du syntes var nødvendig om hvordan tilstanden din kunne utvikle seg i den nærmeste framtid?

Ikke aktuelt Nei, jeg fikk ikke vite noe om det Ja, jeg fikk vite alt jeg trengte

32. Ble du tatt med på råd i forbindelse med videre fysioterapi, hvis du ønsket det?

Ikke aktuelt Jeg ønsket ikke å bli tatt med på råd Nei, alt ble bestemt over hodet på meg Ja, jeg ble tatt med på råd

33. Ble du møtt med høflighet og respekt?

Ja, jeg ble møtt med høflighet og respekt Nei, jeg ble ikke møtt med høflighet og respekt

34. Var følgende forhold tilfredsstillende ved besøket hos fysioterapeuten?

	Ikke aktuelt for meg	Ja, helt tilfredsstillende	Nei, helt uakseptabelt
Avskjermet rom for fortrolig samtale	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Venterommet	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Mulighet til å kjøpe mat og drikke	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Toalettforhold	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Renhold	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Etter konsultasjonen hos fysioterapeuten på poliklinikken

35. Hadde du noen ubesvarte spørsmål da du forlot poliklinikken/dagavdelingen?

Ja, mange Nei, ingen

36. Mener du at du på noen måte ble feilbehandlet (etter det du selv kan bedømme)?

Ikke aktuelt Behandlingen var helt korrekt Jeg ble alvorlig feilbehandlet

37. Hvor tilfreds er du, alt i alt, med den behandlingen du fikk ved poliklinikken/dagavdelingen?

Ikke særlig tilfreds Absolutt tilfreds

38. Hva har besøket ved poliklinikken (så langt) betydd for sykdommen eller helseproblemet ditt?

Passer ikke i mitt tilfelle Ingen vesentlig bedring Det har gjort meg helt frisk, helseproblemet er borte

39. Alt i alt, hvor fornøyd eller misfornøyd er du med konsultasjonen ved poliklinikken/dagavdelingen?

Svært misfornøyd Ganske misfornøyd Både og Ganske fornøyd Svært fornøyd

40. Alt i alt, hvordan var erfaringene dine med poliklinikken/dagavdelingen ved dette besøket?

Mye dårligere enn forventet Noe dårligere enn forventet Som forventet Noe bedre enn forventet Mye bedre enn forventet

Bakgrunnsspørsmål

Opplysningene nedenfor skal brukes til å undersøke om ulike pasientgrupper har forskjellige erfaringer med poliklinikker og dagavdelinger, og det er viktig at du besvarer spørsmålene.

41. **Kjønn og alder:** Mann Kvinne Alder: år

42. **Er morsmålet ditt et skandinavisk språk? (inkludert samisk)** Ja Nei

43. **Hvor mange ganger i løpet av siste 6 måneder har du hatt poliklinikktime?**

Bare denne ene gangen

2 – 5 ganger

Mer enn 5 ganger

44. **Stort sett, vil du si at din helse er:**

a) Utmerket Meget god God Nokså god Dårlig

b) **Hvilket funksjonsnivå har du?**

Bruker rullestol

Går med ganghjelpemiddel

Går alene uten ganghjelpemiddel

45. **Hva gjør du til daglig?**

Er yrkesaktiv Er hjemme-
arbeidende Er uføretrygdet Er sykmeldt /
på attføring Er pensjonist Er under
utdanning Annet

46. **Hvor mange år har du gått på skole / tatt utdanning etter at du var ferdig med obligatorisk grunnskole?**

Antall år

(Obligatorisk grunnskole = 0, alle årene etter grunnskolen legges sammen)

47. **Hvor mange personer bor i husstanden din?**

Jeg bor alene

Vi er 2 personer

Vi er 3 personer eller flere

48. **Kunne du tenke deg å svare på et nytt skjema fra oss om kort tid, dersom det blir aktuelt?**

Sett kryss dersom du kunne tenke deg det

Er det andre erfaringer med undersøkelsen hos fysioterapeuten som du ønsker å formidle?

.....
.....
.....

Tusen takk for at du tok deg tid til å svare!

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Patients Global Impression of Change/ Pasientens overordnede inntrykk av endring

Før undersøkelse og utprøving av fysioterapibehandling på MS-poliklinikken er min evne til å bevege meg (for eksempel: sitte, reise meg, stå, gå) (sett ring rundt det tallet som passer best)

1. veldig mye bedre
2. mye bedre
3. minimalt bedre
4. uforandret
5. minimalt verre
6. mye verre
7. veldig mye verre

--	--	--	--	--

Patients Global Impression of Change/ Pasientens overordnede inntrykk av endring

Etter undersøkelse og utprøving av fysioterapibehandling på MS-poliklinikken er min evne til å bevege meg (for eksempel: sitte, reise meg, stå, gå) (sett ring rundt det tallet som passer best)

1. veldig mye bedre
2. mye bedre
3. minimalt bedre
4. uforandret
5. minimalt verre
6. mye verre
7. veldig mye verre

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Borgs skala over opplevd anstrengelse

Før undersøkelsen og prøvebehandlingen hos MS-fysioterapeuten ber vi deg si noe om hvor anstrengende det er å gå innendørs.

Sett ring rundt tallet som passer best

- 6
- 7 Meget, meget lett
- 8
- 9 Meget lett
- 10
- 11 Ganske lett
- 12
- 13 Noe anstrengende
- 14
- 15 anstrengende
- 16
- 17 Meget anstrengende
- 18
- 19 Meget, meget anstrengende
- 20

--	--	--	--	--

Borgs skala over opplevd anstrengelse

Før undersøkelsen og prøvebehandlingen hos MS-fysioterapeuten ber vi deg si noe om hvor anstrengende det er å reise og sette seg.

Sett ring rundt tallet som passer best

- 6
- 7 Meget, meget lett
- 8
- 9 Meget lett
- 10
- 11 Ganske lett
- 12
- 13 Noe anstrengende
- 14
- 15 anstrengende
- 16
- 17 Meget anstrengende
- 18
- 19 Meget, meget anstrengende
- 20

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Borgs skala over opplevd anstrengelse

Etter undersøkelsen og prøvebehandlingen hos MS-fysioterapeuten ber vi deg si noe om hvor anstrengende det er å reise og sette seg.

Sett ring rundt tallet som passer best

- 6
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- 13 Noe anstrengende
- 14
- 15 anstrengende
- 16
- 17 Meget anstrengende
- 18
- 19 Meget, meget anstrengende
- 20

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Borgs skala over opplevd anstrengelse

Etter undersøkelsen og prøvebehandlingen hos MS-fysioterapeuten ber vi deg si noe om hvor anstrengende det er å gå innendørs.

Sett ring rundt tallet som passer best

- 6
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- 12
- 13 Noe anstrengende
- 14
- 15 anstrengende
- 16
- 17 Meget anstrengende
- 18
- 19 Meget, meget anstrengende
- 20

Appendix 8

Observasjons guide, pasienter

Beskrivelse av rom, pasient mht. alder, kjønn, år siden diagnose, funksjonsnivå.

- Hva skjer innledningen?
 - Hva gjør/sier fysioterapeuten og hva gjør/sier pasienten?
 -
- Hvordan foregår undersøkelsen mht. innhold og interaksjon?
 - Hva vektlegges og hvem bidrar til aktuelle fokus?
 - Fysioterapeutens handlinger – pasientens handlinger?
 - Bruk av hands-on? hvordan og hva skjer i samhandlingen
 - Endringer i bevegelseskvalitet – bedring? Forverring?
 - Andre endringer hos pasienten?
 -
- Hvordan vektlegges råd og veiledning og hvordan foregår det?
 - Pasientens reaksjoner og uttrykk?
 - Fysioterapeutens handlinger
- Avslutning - hva foregår, hva vektlegges, hvem gjør hva?

Appendix 9

Observasjons guide, veiledning av kommunefysioterapeuter

Beskrivelse av rom, pasient mht. alder, kjønn, år siden diagnose, funksjonsnivå og fysioterapeuten mht. erfaring med PwMS.

- Hva skjer innledningen?
 - Hva gjør/sier fysioterapeuten, pasienten og kommunefysioterapeuten ?
 -
- Hvordan foregår veiledningen mht. innhold og interaksjon?
 - Hva vektlegges og hvem bidrar til aktuelle fokus?
 - Hva driver veiledningen ?
 - Fysioterapeutens handlinger, og hva leder det til?
 - Pasientens handlinger, og hva leder det til?
 - Kommunefysioterapeutens handlinger, og hva leder det til?
 - Bruk av hands-on vs. Verbal formidling
 -
- Hvordan vektlegges råd og veiledning mht. videre behandling, og hvordan foregår det?
 - Kommunefysioterapeutens reaksjoner og uttrykk?
 - Pasientens reaksjoner og uttrykk
 -
- Avslutning - hva foregår, hva vektlegges?

Appendix 10

Temabasert intervjuguide

(For intervju av MS-pasienter)

Bakgrunnsinformasjon: Tidspunkt for diagnose, EDSS, bosted, sosial situasjon, fysioterapi i kommunen?

1. Hva er hovedinntrykket ditt etter fysioterapikonsultasjonen ved MS-poliklinikken?
Oppfølgingstema:
 - a. Organisering, timing, varighet?
 - b. Innhold ?
 - c. Andre ting du vil trekke frem?
2. Hvilke erfaringer har du med konsultasjonen med fysioterapeuten på MS-poliklinikken?
 - a. Hva ble vektlagt og hva tenker du om det?
 - b. Er det noe du ville ha ønsket mer/mindre vektlagt?
 - c. Fortelle konkret om deler av konsultasjonen - hva de gjorde og tanker/refleksjoner rundt disse erfaringene
 - d. Andre erfaringer og tanker du har lyst til å formidle?
3. Refleksjoner knyttet til erfaringer gjennom kropp og bevegelse i løpet av konsultasjonen
 - a. Fortelle/beskrive konkrete erfaringer fra konsultasjonen hvor fysioterapeuten brukte hands-on teknikker i undersøkelse og behandling
 - b. Erfarte du noen endringer? Dersom endringer: Beskrive hvilke og når de skjedde osv. (etterspørre både positive og negative), hva betydde de?
 - c. Etterspørre beskrivelser og erfaringer fra konsultasjonen der det fra observasjonen fremgår lite – mye engasjement, skjer bedring/forverring i bevegelseskvalitet
 - d. Andre erfaringer, opplevelser fra konsultasjonen som du vil dele?
4. Hvordan opplevde du at egentrening ble berørt i løpet av konsultasjonen med fysioterapeuten?
 - a. Utdype hvordan egentrening ble formidlet?
 - b. Tanker rundt mulighet, interesse for å drive egentrening?
 - c. Eksempler på instruksjon i egentrening – relevans?
5. Andre opplevelser, tanker og erfaringer relatert til fysioterapikonsultasjonen som jeg ikke har spurt om som du ønsker å formidle?

Vektlegge åpne spørsmål, oppfølgingsspørsmål relatert til (video)observasjonen i forkant, gjentakelse av svar for å kvalitetssikre egne forståelse av hva informantene har formidlet.

Appendix 11

Interview guide **Community physiotherapists, cPTs**

1. Reflections regarding the report from the physiotherapist at the out-patient clinic (oPT).
 - What reflections do you have with regard to the report?
 - What do you think about the content?
 - What did you gain from reading it?
 - What about the relevance of the report for your further treatment?
 - What do you think about the language used?
 - Could describe a report that you considered informative?
 - Could describe a report that you considered less or non-informative?
 - Other things that you consider important with regard to reports?

2. Positive and negative experiences from the guidance setting
 - What reflections do you have after having participated in the guidance session?
 - What do you think about the content and setting?
 - Could you describe how you experienced the different parts of the session?
 - What were the strengths and weaknesses in this guidance session?
 - Could you describe parts of the session that was important for you?
 - Could you describe parts of the session that were less or unimportant for you?
 - What do you think about your own participation during the session?
 - What do you think about communication between you and the oPT?
 - Which patients do you need guidance to treat?
 - Other aspects you consider important with regard to the guidance?

3. Implications for subsequent treatment
 - What do you think this guidance session will imply for your subsequent treatment of the patient?
 - Can you describe aspects from the guidance that you have tried out in your own treatment or are going to try out?
 - What are the challenges for implementation of such guidance in your everyday practice?
 - What do you think you will do in your next treatment with patient x?
 - Are there aspects in the guidance that could have been conducted in other ways? What? Could you describe?
 - Other comments?

Other follow-up questions were established in the setting depending on what came up in the conversation, and the interviewer often used phrases such as: Could you deepen or describe? What did you mean? Could you specify more? Etc.

Appendix 12. Overview of the analysis from Papers I-III

		<i>Body and movement in sense making and professional development</i>	
Overall theme	<i>Participation</i>	<i>Perceptions of change and sense making</i>	<i>Knowhow and continuity of care</i>
Sub-theme Results from Papers I	<p>-High expectations regarding the consultation with the physiotherapist regardless of ambulation level.</p> <p>-Very high satisfaction with all aspects of the physiotherapy consultation regardless of their age, gender, expectations, level of ambulatory independence, and if they had seen one or two additional professionals on the team during one day.</p> <p>-PwMS's perceptions of movement during the consultations, embedded in the oPT's explanations focusing on inter-relating the patient's sensory-motor dysfunctions to the patient's problems with ADL, expanded the PwMS's knowledge regarding their own situation.</p> <p>-The oPT's use of a handling and demonstrations in the interactions with the patients informed the patients more than words alone. PwMS's active performance of movement and the perceptions of self-movement during the consultation enriched the verbal dialogue with the oPT.</p>	<p>-Very high satisfaction after the physiotherapy consultation; nearly half of the subjects reported some degree of impact on how they perceived their disease or health problem.</p> <p>-Half of the sample reported that the physiotherapy consultation was as expected, whereas the rest claimed that it was somewhat better to "much better" than expected.</p> <p>-The PGIC showed that 35 subjects (57 %) reported minimal to great improvement, whereas 26 (43 %) reported no change in walking and standing up/sitting down. The BRSPE showed significant reduction in reported exertion during the activities.</p> <p>-Self-perceived changes in the quality of movement, mostly improvements but also worsening during the consultation, were reported. Improvements were better physical contact between the feet and the floor, better flexibility in the ankles/feet when standing, a more upright position and a perception of easier balancing and walking. Worsening was associated with tiredness and heavy legs. The perceived improvements surprised the PwMS and provided direction regarding limitations and possibilities of motor function. Furthermore, the perceptions of improvement augmented the PwMS's attention during the situations and increased the credibility attributed to the advice given by the physiotherapist regarding self-assisted exercises.</p>	<p>-Very high satisfaction with the collaboration, the organisation of the service, time for conversation with the physiotherapist and pre-visit information regarding physiotherapy.</p> <p>-Practical hand-on guidance in self-assisted exercises was reported as a vital in the session, particularly for exploring new and more optimal movement strategies. The less disabled patients considered that they could profit from this advice, while the more disabled patients did not consider themselves as capable of doing the exercises on their own.</p> <p>-Access to physiotherapy in the OP clinic from the initial phase and throughout the course of the disease was requested.</p>
II	<p>-The oPT's use of a handling and demonstrations in the interactions with the patients informed the patients more than words alone. PwMS's active performance of movement and the perceptions of self-movement during the consultation enriched the verbal dialogue with the oPT.</p>	<p>-The cPTs emphasised the importance of participation in exploratory treatment aiming to achieve improvement in motor performance accompanied by verbal reflections and discussions during the action. Observations of changes in performance of balance and walking during the session appeared important both for strengthening the movement analyses and for providing directions for further treatment.</p>	<p>-Reflections on action, without the patient present, appeared to be essential for the cPTs' professional development. Particularly, clinical reasoning regarding the hypothesis of why the patient was moving the way he/she was and goal-setting.</p> <p>-Experienced cPTs expressed capability for implementing some of the advice in subsequent treatments, however, the less experienced cPTs found this process to be difficult.</p> <p>-Supervision while the cPTs handled and treated the patient was requested from the cPTs as was more plain language in the patient reports and strengthening the cPTs perspective.</p>
III	<p>-The cPTs highlighted participation in authentic movement analysis of a familiar patient as vital. An important aspect of this joint investigation of why the patient had his/her problems with ADL, performed through observation and handling was the oPT's verbalised reflections during the session</p>		



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