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MULITPROFESSIONAL REHABILITATION FOR WOMEN WITH FIBROMYALGIA QUANTITATIVE AND QUALITATIVE STUDIES

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To Berit and Tage

ABSTRACT

The overall aims of the present work were to obtain further knowledge of the effects of multiprofessional rehabilitation programmes for women with fibromyalgia (FM) or chronic widespread musculoskeletal pain (CWMP) and to elucidate what strategies women with FM use and find successful in controlling their symptoms. The underlying purpose was to improve rehabilitation further and thereby increase the possibilities for these women to live actively, return to work and continue working.

The Study I was a prospective, non-randomised intervention trial with 43 women with FM or CWMP who were assigned consecutively to a multi-professional rehabilitation programme or to a waiting-list control group. Comparisons were made of e.g. movement quality. Study II was an exploratory analytical study where 16 of the women from study I were interviewed. Grounded theory analysis was used to explore what the women remembered and what they had gained from the rehabilitation programme one year after discharge. Study III, an exploratory analytical study with emergent design, explored what strategies 12 women at work despite FM used to control pain, fatigue and other symptoms. Data was collected with diaries, focus group discussions and interviews, and processed using content analysis and grounded theory. Study IV was a prospective, non-randomised intervention trial, where muscle activity in the trapezius, infraspinatus and extensor digitorum were measured with surface EMG during one work task and three domestic tasks before and after a rehabilitation programme, in 16 women with FM and in 10 healthy controls. Pain intensity and perceived exertion were rated after every task.

The interventional rehabilitation programmes improved quality of movement assessed with Body Awareness Scale -Health, reduced experience of vegetative disturbances in women with FM/CWMP (study I) and enabled FM women to perform tasks with decreased muscle activity (study IV). A decrease in perceived exertion coincided with the decrease in muscle activity. During the rehabilitation programme, the women with FM/CWMP followed a process ‘from shame to respect’. They began to listen to their bodies, setting limits and improving in self-image (study II). To manage work despite FM, the women fought ‘a constant struggle’ against the consequences of their illness and prejudices in their surroundings (study III). They had brought a positive spirit to a variety of active strategies. To manage the struggle the women emphasised the importance of having grieved the loss of the way they used to live their lives. Support from others, especially their families, facilitated the struggle.

The studies demonstrate that women with FM/CWMP can benefit from multiprofessional rehabilitation in various ways, e.g. with a change in their movement behaviour towards an increased general movement quality, and the ability to perform tasks with a decreased muscle activity in shoulder-arm muscles. A respectful encounter with staff and with others in the same situation, together with body awareness training, might help women with FM/CWMP to begin respecting their own limits and to change positively in self-image. Many strategies, e.g. setting limits, taking care of one-self and being knowledgeable were described as valuable for managing pain and other symptoms.

Key words: multiprofessional rehabilitation, qualitative studies, strategies, fibromyalgia, chronic widespread musculoskeletal pain, body awareness, movement quality, EMG, muscle activity

SAMMANFATTNING (SUMMARY IN SWEDISH)

Avhandlingens övergripande syftet var att ytterligare öka kunskaperna om effekterna av multiprofessionella rehabiliteringsprogram för kvinnor med fibromyalgi (FM) och långvarig generaliserad muskuloskelettal smärta (CWMP), samt att öka kunskaperna om vilka strategier kvinnor med FM använder och tycker är verksamma för att kontrollera sina symptom. Allt detta med syftet att vidare förbättra rehabiliteringen och därmed öka möjligheterna för dessa kvinnor att leva aktivt, återgå i arbete och kunna fortsätta arbeta.

Olika metoder användes i de i avhandlingen ingående studierna. Studie I är en prospektiv, icke-randomiserad interventionsstudie med 43 kvinnor med diagnoserna FM eller CWMP som konsekutivt fördelades till en behandlingsgrupp i ett multiprofessionellt rehabiliteringsprogram eller till en väntelistekontrollgrupp. Jämförelser gjordes i rörelsekvalitet, olika aspekter av smärta och livskvalitet. Studie II är en explorativ analytisk studie där 16 kvinnor från behandlingsgruppen i studie I intervjuades. Analysen som genomfördes enligt 'grounded theory' utforskade vad kvinnorna kom ihåg och vad de hade nyttat från rehabiliteringsprogrammet ett år efter avslutande. Studie III är en explorativ analytisk studie med en emergent design, som utforskade vilka strategier 12 kvinnor, som yrkesarbetade trots FM, använde sig av för att kontrollera smärta, trötthet och andra symptom. Data insamlades med dagböcker, fokusgruppsdiskussioner och individuella intervjuer.

Analysen gjordes enligt innehållsanalys och 'grounded theory'. Studie IV är en prospektiv, icke-randomiserad interventionsstudie, där muskelaktiviteten i trapezius pars descendens bilateralt, infraspinatus och extensor digitorum på dominant sida, mättes med yt-EMG hos 16 kvinnor med FM och 10 friska åldersmatchade kontroller. Mätningarna genomfördes när försökspersonen genomförde fyra uppgifter: en skrivuppgift vid dator i 3 min, att hälla vatten i 5 glas, att stryka en herrskjorta i 3 min samt att dammsuga i 2 min. Kvinnorna med FM mättes före och efter ett rehabiliteringsprogram, de friska mättes med samma tidsintervall. Smärtintensitet och upplevd grad av ansträngning, mättes med Borg CR 100 skalan efter varje enskild uppgift.

Resultaten i studie I och IV visade att de utvärderade rehabiliteringsprogrammen var till nytta för kvinnorna med FM och CWMP. Kvinnorna med FM/CWMP förbättrades i rörelsekvalitet och minskade upplevelsen av vegetativa störningar (studie I) och kvinnorna med FM kunde utföra uppgifter med lägre grad av muskelaktivitet efter rehabiliteringen (studie IV). En minskning i upplevd ansträngning sammanföll med minskningen i muskelaktivitet (studie IV). Under rehabiliteringsprogrammet blev kvinnorna med FM/CWMP delaktiga i en process, 'från skam till respekt'. De började lyssna till kroppens signaler, sätta gränser och förbättrade sin självbild (studie II). För att klara att fortsätta arbeta trots FM, kämpade kvinnorna en 'ständig kamp' mot konsekvenserna av sjukdomen och omgivningens fördomar (studie III). De hade tillägnat sig en mängd aktiva strategier som de använde i positiv anda. För att klara kampen, betonade kvinnorna vikten av att ha sörjt förlusten av det liv de kunde leva tidigare. Stöd, särskilt från familjen, underlättade kampen.

Studierna visar att kvinnor med FM/CWMP kan ha nytta av multiprofessionell rehabilitering på olika sätt, till exempel genom förändring av rörelsebeteendet mot en ökad rörelsekvalitet och genom att kunna utföra uppgifter med minskad aktivitet i skulder-arm-muskulaturen. Ett respektfullt möte med personal och andra i samma situation tillsammans med träning i kroppskännedom kan hjälpa kvinnor med FM/CWMP att börja respektera sina egna gränser och positivt förändra sin självbild. Många olika strategier, som till exempel att sätta gränser, ta hand om sig själv och vara kunnig, beskrivs som värdefulla för att klara smärta och andra symptom.

LIST OF PUBLICATIONS

The thesis is based on the following publications, which are referred to in the following text by their Roman numerals.

- I. Gustafsson, M., Ekholm, J., and Broman, L.
Effects of a multiprofessional rehabilitation programme for patients with fibromyalgia syndrome.
J Rehab Med 2002; 34: 119-127.
- II. Gustafsson, M., Ekholm, J., and Öhman, A.
From shame to respect: musculoskeletal pain patients' experience of a rehabilitation programme, a qualitative study.
J Rehab Med 2004; 36: 97-103.
- III. Löfgren, M., Ekholm, J., and Öhman, A.
'A constant struggle': Successful strategies of women in work despite fibromyalgia.
Accepted for publication in Disability and Rehabilitation 2005-06-02.
E-published ahead of publication.
- IV. Löfgren, M., Broman, L., and Ekholm, J.
Does rehabilitation decrease shoulder muscle activity in fibromyalgia? An electromyographical study.
Manuscript 2006.

The author changed family name from Gustafsson to Löfgren 2005.

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ABBREVIATIONS

Basic BAT *basic body awareness therapy*

BAS *body awareness scale*

BAS-H *body awareness scale-health*

CWMP *chronic widespread musculoskeletal pain*

S-EMG *surface electromyography*

EMG-biofeedback *electromyography biofeedback*

FGD *focus group discussion*

FM *fibromyalgia syndrome*

µV *microvolt*

%subrefEMG *µV during task divided by µV during sub-maximal reference contraction*

DEFINITIONS

A strategy indicates an activity, e.g. here what people actively do in the context of an illness to mobilise resources and maximize results.

Chronic pain is considered to be chronic when it has been persistent or regularly recurrent for more than three months during the previous three months (1).

Chronic widespread pain according to the 1990 American college of Rheumatology (ACR) criteria, pain is considered widespread when present in both sides of the body and above and below the waist. In addition, axial skeletal pain should be present (2).

Coping strategies are the strategies people develop to manage stressful life situations: how people manage stress and strain. In stress research different coping styles are defined and studied (3). However, in this thesis the word 'coping' is used in a wider sense of everyday language: a synonym for managing one's own situation, without theoretical implications.

Disease refers to sickness as a physiological process: it can be described in an objective way, with measurements that can verify a deviating medical/physiological value (4,5).

Empowerment is about women and men taking control over their lives: being able to perceive alternatives, make choices and fulfil these choices. It is both a process and an outcome, individual and collective. Women's empowerment is essential to achieve gender equality. Outsiders cannot empower women, only women can empower themselves. However, institutions can support empowering processes at both individual and collective levels (6).

Gender refers to the economic, social and cultural attributes and opportunities associated with being a man or a woman, comprising the constant changes in being that take place in interaction with the environment in every culture at particular points in time (7, 8).

Illness refers to the person's subjective experience, perception and behaviour. Knowledge about it can only come from the persons' own descriptions, unlike disease, which can be identified independently of the sufferer's statement (4).

Multidisciplinary team refers to the efforts of practitioners from a number of disciplines. It may be a group of specialist physicians with different medical specialities, or a team of many different professions working together in rehabilitation (9).

Multiprofessional rehabilitation team is a team whose members are from different professions and working together to give a certain patient the best possible rehabilitation outcome (9).

Rehabilitation is a process aiming to restore an individual who suffers from disorder or loss of physical or psychological function, to an independent life with the best possible function and prerequisites for independence. Measures can include workplace changes or action of a medical, psychological or sociological nature. All measures should be based on the individual's condition and needs'. (Department of Health and Welfare, Sweden)

Rehabilitation back to work aims at recreating a person's working capacity and self-maintenance ability after he or she has recovered from sickness.

Sex refers to the biological characteristics that define humans as female or male (7).

Sickness is society's norms and values about what health is and what ill-health is (4).

INTRODUCTION

PAIN AMONG WOMEN AND FIBROMYALGIA SYNDROME

The work reported in this thesis focused upon rehabilitation for women with fibromyalgia syndrome (FM) and chronic, widespread musculoskeletal pain (CWMP).

Pain is common in the general population, and most common among women. Postal questionnaire studies investigating the prevalence of chronic, widespread pain in the general population in the USA, the UK and Sweden indicate a frequency of 10-11% of generalised pain (without allodynia) (1, 10, 11). Chronic generalised pain and regional pain are both 50% more common among women than among men (11). The prevalence of FM in western countries is about 2% (10, 12), including 3.5% of women and 0.5% of men, making FM a common diagnosis among women suffering from musculoskeletal pain. The condition is mostly permanent, making the prevalence highest in women over 60 (10).

In Sweden, approximately 175 000 women fulfil the criteria for FM: it can thus be considered a common disease among women.

FM diagnosis

The diagnosis FM is based on long-standing, widespread pain and tenderness. The criteria for the diagnosis were set 1990 by the American College of Rheumatology (ACR)(2):

1. Widespread pain: pain in all four quadrants (left and right sides, upper and lower halves of the body, and axial pain).
2. The pain must be longstanding i.e. present for more than three months.
3. The person should express pain on palpation with moderate pressure at eleven of eighteen specified locations.

The presence of generalised allodynia/hyperalgesia, pain due to a stimulus that does not normally provoke pain/provoke an increased response to a stimuli which is normally painful (13) distinguishes FM from other longstanding muscular pain conditions where allodynia/hyperalgesia is not generalised (2). Other common symptoms are fatigue, stiffness, sleep disorders, cognitive problems, decreased muscular endurance, bowel and bladder problems and psychological symptoms such as depression and anxiety.

The symptoms and associated disability of FM are aggravated by e.g. stress, anxiety and too much physical activity.

Chronic widespread musculoskeletal pain (CWMP) diagnosis

In studies I and II the participating women had diagnoses FM or CWMP. The diagnosis CWMP was used according to the ACR criteria, namely pain considered widespread when present in both sides of the body and above and below the waist. In addition, axial skeletal pain should be present (2). Exclusion criteria from studies I and II were pain associated with serious disease or injury, misuse of drugs, or serious psychiatric disease. The main difference between the two groups was that the women with CWMP did not fulfil all the criteria for FM, e.g. some tender points could be missing. Clinically the two groups of patients were similar and they all deteriorated in consequence of strenuous physical exercise. In what follows, FM/CWMP is used in studies I and II, FM in studies III and IV.

The overall aim of the work was to evaluate existing rehabilitation measures for women with FM and CWMP and to explore, from the women's viewpoint, how rehabilitation can improve further.

LOCATING MYSELF

I have been a physiotherapist for 16 years, working mainly with rehabilitation for women with chronic musculoskeletal pain. After graduation, I had the luck to get my first position at a rehabilitation centre in southern Norrland, where the rehabilitation was managed with multiprofessional teams. Teamwork was a great source for understanding the complexity of chronic pain. During the years around 1990, women with a ‘different’ pain condition came to the centre in increasing numbers. This pain condition was called ‘muscle rheumatism’, ‘fibrositis’ or ‘fibromyalgia’ (FM). The women experienced constant pain but we could not really help them within our usual programmes. Most felt no better for the exercise, massage and other treatment we offered; some even deteriorated. We tried a new approach, having heard about ‘pain education’.

Since then, knowledge and understanding of chronic pain and the mechanisms leading to FM has grown. I have continued to work with rehabilitation for women with FM, and as a practitioner have benefited from scientific progress, especially since moving to Stockholm and the Karolinska Hospital, collaborating with researchers at the Karolinska Institutet. Although there is still much we do not understand about chronic pain, we understand more about rehabilitation for – and the needs of – patients with FM.

In the present research project, my particular background was very important. My early curiosity about these women, their mysterious pains and other symptoms, and the reality lived by those who experience continuous pain, have been an important driving force. The original questions of the research project evolved from my everyday clinical work. The third and fourth studies presented below grew out of questions emerging from the first two.

With this experience from rehabilitation – and especially multiprofessional pain rehabilitation – my kind and level of pre-understanding (14) is obvious. Some may claim that my personal commitment and pre-understanding, my pre-conceived knowledge are sufficiently extensive to preclude new perspectives on the phenomena studied; are a disadvantage and an obstacle to studying rehabilitation for women with FM or CWMP. In discussion throughout the project, I and my co-authors have indeed shared reservations as to methodology and analysis.

The practical knowledge from many years of clinical work has been used in the process of analysis, which has been of value. However, I have tried to keep my own pre-understanding firmly within bounds (14).

THEORETICAL FRAMEWORK

Many factors influence how well rehabilitation for women with FM and CWMP succeeds. The work reported in this thesis took place during a period in which medical knowledge of chronic pain was rapidly increasing, rehabilitation methods developing, and the awareness of how gender issues influence medical care expanding. The three perspectives pain pathophysiology, rehabilitation and gender theory together form a theoretical framework within which the present results will be discussed. These perspectives are among those influencing perceptions of patients with FM/CWMP, making it easier to understand their pain and other symptoms and to design better rehabilitation programmes.

Pathogenesis

The literature discusses different models for the pathogenesis of FM.

1. Fibromyalgia is a musculoskeletal pain condition characterised by multifocal pain and generalised allodynia/hyperalgesia (2). In this model FM is seen as the final stage in a process starting with protracted local or regional musculoskeletal pain (10, 15). Stress-related symptoms are considered to be secondary to pain and pain hypersensitivity.
2. Fibromyalgia is a chronic stress syndrome where pain is one of many possible biological or psychosocial stressors. FM overlaps with other similar somatic disorders such as chronic fatigue syndrome and irritable bowel syndrome. In this model, pain is secondary to chronic stress, which can be biological or psychosocial (16).
3. Fibromyalgia is described as a medically unexplained syndrome with increased rates of depression, anxiety and psychological distress (17). In this model, emotional symptoms may dominate in people with pronounced pain response and no biological changes mentioned.

Although the exact aetiology of FM is thus still unknown, alterations have been found in several organ systems including the central nervous system. Most researchers agree with the hypothesis that FM is a multi-factorial syndrome; both the ‘pain model’ and the ‘stress model’ are commonly present in the same patient.

Research during the past few decades has provided a new understanding of the pathophysiology of chronic pain. FM is suggested to be one end of a continuous spectrum (10, 15) where chronic pain extends from regional to widespread pain ending in FM. In a three-year follow-up study of the prevalence of no pain, chronic regional pain and chronic widespread pain in the south west of Sweden, Bergman (18) showed that there was a large (30%) movement between the pain groups, in which the majority of those who developed widespread pain after three years came from the group with regional pain. Changes were also seen in the opposite direction, towards less or no pain. It was possible, then, to become pain-free. The generalised, migrating pain and tenderness characterizing patients with FM are today explained with alterations in the central nervous system (19, 20, 21). FM and similar pain disorders have abnormal, hyper-sensitive pain processing (19, 20, 22), with lowered mechanical and thermal pain thresholds (23) and altered temporal summation of pain stimuli (24). How pain sensations are perceived and expressed depends both on the neurophysiological sensation and the emotional response, and also on social circumstances. A biopsychosocial perspective is important for understanding these mechanisms. Other alterations such as disturbances in muscular energy metabolism (25, 26), in the neuro-endocrinological system (27, 28) and in stress responses (29) are thought to contribute to the problem. In the muscles, disturbances in intra-muscular microcirculation and muscular energy metabolism (25) are seen, as are increased muscle tension and decreased output during dynamic activity (26).

Treatment and rehabilitation aim at alleviating symptoms and helping find strategies to manage life and work despite pain and other symptoms – there is yet no cure.

Consequences for daily life and work

Living with continuous pain, fatigue, disrupted sleep, tiredness and muscle weakness has a severe impact on daily life (30, 31, 32, 33, 34, 35). Patients with FM report how they have changed their way of living; e.g. everything has to be done at a slower pace, there is more reliance on help from others, avoidance of heavier tasks and more time spent resting. The fluctuation in symptoms makes it difficult to plan daily life (31, 32). FM symptoms have a major negative effect on work ability. Work disability among patients with FM (30, 33) varies

between 25% and 50%. In a Swedish study (34) of 176 women with FM, 50% were employed, 15% full-time and 35% part-time. Ninety-nine percent reported that FM symptoms affected their work ability. Changes of working hours and work positions/tasks were common in the group who continued working.

Multiprofessional pain rehabilitation

Theoretical aspects

Rehabilitation aims at restoring reduced function caused by disease, illness or injury. The role of rehabilitation differs depending on how ill-health is viewed. In a biomedical model, rehabilitation efforts are directed towards the functional consequences of a defined disease. When a biopsychosocial, holistic model is used, ill-health and its implications in a social context are considered (36). In multiprofessional rehabilitation the holistic model is emphasised.

Individual adjustments in rehabilitation

Multiprofessional and cognitive-behavioural programmes have significant and lasting effects for patients with FM (37, 38). However few patients are able to attend such rehabilitation programmes.

Physical exercise is an important part of multiprofessional rehabilitation. As knowledge of the physiology of chronic pain has increased, the view of how patients with FM can perform exercise has changed, and rehabilitation programmes for patients with FM have improved in consequence. The delicate balance between improving physical function and worsening the pain means that training programmes have to be individually adjusted. The patient always has to balance improved function against increased pain intensity or frequency.

Physical, social and psychological factors interact in FM. A holistic perspective, where every patient's individual situation is in focus, is important when considering rehabilitation measures.

It is important that rehabilitation measures are introduced at the right moment. Gullaksen showed how the ability of patients' with chronic pain to accept a new situation and cope with it – described as life adjustment – comes after some time (39). On the other hand, rehabilitation has to start early enough to prevent longstanding sickness absence and disability pension. Individual motivation and readiness to adjust have to be taken into account when planning for rehabilitation back to working life.

Rehabilitation back to work

Sweden, Norway and the Netherlands have the highest levels of sickness absence in western Europe (40, page 33). In Sweden between 2000 and 2003, 14% of the population aged between 20 and 64 were on sickness allowance (40, page 29). Musculoskeletal pain is the most common reason for sick leave and disability pension (40, 41, 42 page 35). Of those receiving sickness benefit or disability pension due to musculoskeletal pain, women are in the majority (43).

In Sweden employers have extensive responsibilities for rehabilitation for work resumption, mainly for early rehabilitation measures within the resources of the organisation.

Rehabilitation for work resumption is managed in many different settings. The regional social insurance offices are responsible for co-ordinating work-oriented rehabilitation, often provided by different rehabilitation actors. The offices have appropriations for the purchase of vocational rehabilitation from various sources, usually multi-professional teams at departments of rehabilitation medicine. However, rehabilitation categorised as medical care is a responsibility of the county council, which thus finances pure medical rehabilitation with no aim of work resumption.

Several official government reports have concluded that co-ordination among rehabilitation actors is insufficient, yet no major changes in the content or directions of the activities have taken place (44 page 272).

Studies show that one Euro invested in comprehensive rehabilitation gives nine Euros back (45). Yet most people with chronic pain conditions never get any rehabilitation, and if they do, the measures begin late, with a median time from sick-listing to active rehabilitation of 200 days in 2003 (44). The effects of different rehabilitation measures are debated. Modified work training at the workplace is common. An evaluation by the Swedish national insurance offices found that although rehabilitation measures were offered equally to men and women, women were more often given the cheaper workplace training while men were in education/training (46). Opinions differ as to the effects of work training. Van Duijn et al. (47) could not demonstrate any effect of work training alone on work return after sick-leave due to musculoskeletal complaints. In a context with a more extensive rehabilitation programme for patients with chronic back-pain, work training at the workplace was, however, effective (48). Jensen (49) demonstrated that full-time, multidisciplinary rehabilitation with a behavioural approach was effective in improving health and increasing return to work in women with back/neck pain, while it had no or little effect on men with the same problems. Possible reasons for this will be further treated in the Discussion. In a study by Liedberg (50) young women with FM in Sweden and the USA showed a high level of work disability already in the first year after diagnosis. Factors that predicted unemployment were younger age, lower physical functioning, lower self-efficacy and more severe symptoms. The possibilities of, and problems related to, rehabilitation to facilitate work resumption for these women need further investigation.

Multiprofessional medical rehabilitation for work resumption

Multiprofessional pain rehabilitation is managed in different settings. These include regional medical care (rehabilitation medicine), primary health care, occupational health services, employment offices, social services, regional social insurance offices and many private companies. Systematic evaluations (37, 51, 52) for patients with FM/CWMP advocate multiprofessional rehabilitation, with most evidence supporting cognitive behaviour therapy and general aerobic exercise. Stress management and patient education also benefit patients with FM/CWMP, although trials of higher quality are required to confirm their effectiveness (52). Karjalainen et al. (52) concluded in a Cochrane review that evidence for effects of multiprofessional rehabilitation is low in treating FM/CWMP patients, while Goldenberg et al. (37) found strong evidence for its effectiveness for patients with FM. Monotherapies are less effective (37, 51, 52). A study by Lemstra and Olszynski compared a low-cost multidisciplinary rehabilitation programme in a group setting with standard care with the patient's family physician (38). The rehabilitation programme was effective in increasing health status. However no measures for work return were included in the programme and no effects were seen on work resumption.

Gender theory, health and pain

Gender is an abstract concept used in different ways in the literature. According to the World Health Organisation (WHO) definition gender refers to the economic, social and cultural attributes and opportunities associated with being male or female at a particular point in time. Sex refers to the biological characteristics defining humans as female or male (7). In the present thesis, the use of the concept sex comprises the biological differences, while gender considers the cultural and psychosocial perspective of being a man or a woman (8), and the continual changes in being a man or a woman that take place in interaction with the environment in every culture and time: gender is a construction in our consciousness. In

medicine, gender is often used synonymously with sex. In gender theory, the concept is viewed as an analytical category that permeates and affects all other social categories, with a strong structuring effect on individuals and society. Thus the analysis of power hierarchies with gender is the main issue (53, 54). Gender is here considered the strongest of all social categories: we are all constantly involved in reproducing the gendered order (53).

The theoretical gender perspective of power hierarchy has been discussed in medical science and health care/ medical rehabilitation (55, 56, page 249).

Research on gender in a gender-theory perspective is rare in rehabilitation medicine. When sex and gender *are* analysed, this is mostly as statistical background factors, not in relation to any theoretical perspective. Ahlgren (57) and Steinhaug (58) are two of a few exceptions. Ahlgren showed that the rehabilitation process favours men's return to work. Steinhaug showed how rehabilitation can empower women by recognition. She advocates the possibilities of supporting the rehabilitee's own resources in the rehabilitation process. In research on FM and other chronic pain conditions, the gender- theory perspective is more common and has been used by e.g. Hamberg and Johansson (59, 60), Söderberg (61, 62) and Malterud and co-workers (63, 64, 65). But as yet, only very few research projects include the gender perspective even though FM/CWMP is mainly a woman's illness. Fausto-Sterling (66) discuss the implications of the failure of scientific research to consider the gender issue.

Medical science has traditionally focused on the biological models, but behavioural and social aspects are now gaining increased attention, although less has been paid to gender aspects.

This thesis seeks to further integrate the gender perspective with rehabilitation medicine.

Gender is a vast area with many frameworks, theories and perceptions. I employ perspectives from two gender theories, namely Harding's (54) and Hirdman's (53). In different ways, the two models explain phenomena important to rehabilitation.

Harding (54, page 18), considers gender on three conceptual levels: structural, symbolic and individual. An example of the structural level is the gendered division of paid and unpaid work, where men are supposed to support the family and women to take care of the children and domestic work. Other examples are the gendered division in the Swedish labour market (40) where women work mainly in service and care and in inferior positions, while men work in technology or in superior positions.

The symbolic dimension in Harding's model (54) includes norms for everything that is socially or culturally connected with femininity and masculinity. Our thinking about the world is gendered: the norms are about behaviour, appearance and character, sometimes explicit but more often tacit. Men, according to Harding (54) are expected to be rational and independent, women emotional and dependent.

The individual dimension represents issues connected with identity, the individual socialisation of what is socially accepted in being a man or a woman.

Perceptions of femininity and masculinity differ between cultures and times.

Hirdman's model (53) uses the concept 'gender system'. With this model she analyses gender at a societal level. She emphasises that the relations between men and women form a system characterised by separation and hierarchy. The separation keeps men's domination over women and gives men advantage and preferential right of interpretation. Men are regarded as the norm, women as different. Women's subordination and the relations of power between men and women become visible in the concept gender system.

Hirdman argues that the gender system structures all other systems in society, private as well as professional (53). Domestic work (54) and caring for children have not been considered as work or as real activities, but as natural labour which every woman does naturally. Gender scholars emphasise the importance of remembering that women living with similar disabilities experience different problems (67). It is not desirable to make one category and include all

women because they are women: class, ethnicity and other social categories also have to be considered.

The pathophysiological aspect of FM, our knowledge of rehabilitation for women with FM and the influence of gender relations together constitute the tripartite theoretical framework of the present thesis. Within this framework I triangulate the results with the different theories. The three perspectives are from different scientific traditions and therefore sometimes hard to reconcile.

Disease, illness and sickness

The definitions of disease, illness and sickness are of great importance to those who contract FM and CWMP.

Disease is defined as ill-health coming from an objective, observable phenomenon due to biomedical changes. Diseases are often diagnosed with laboratory tests or other diagnostic methods, and can be classified according to the WHO ICD-10 international classification system. Illness is on the contrary what the human being actually experiences as ill-health. It is a subjective experience and depends on culture and experience.

Sickness is society's norms and values about what health and ill-health are (4).

Medicine traditionally views the body and health biologically (68). Disease has a high status and illness a low status (69, 70). Malterud argues that women more often suffer from diffuse illness (71), i.e. chronic conditions where medical examination gives few objective findings; and that these are poorly classified in the diagnosis system (63).

The etiology of FM is not yet fully understood. In a study by Åsbring (72), physicians described how they, from a biomedical point of view, were sceptical towards conditions, illnesses whose existence could not be proved using objective measures. Patients with FM did not look or behave as the responding physicians expected a sick person to do. Several reported that they hesitated to diagnose a patient with FM, seeing a risk that the patient might became illness-fixated.

Several studies have described the importance of getting a diagnosis and of being treated with respect by health care practitioners (30, 65, 72, 73, 74). In a study by Åsbring, (72) women with FM and chronic fatigue syndrome (CFS) reported that their moral integrity was being questioned, which they felt deeply violating. Werner showed (65), the importance for a patient of being met with recognition. Recognition enables patients to take charge of their own recovery, to gain 'recovery competence'.

White investigated health status after the FM diagnosis (74), showing that receipt of a diagnosis had significantly improved health satisfaction and reduced symptoms three years later.

Physiotherapy practice for patients with FM

Physiotherapy practice aims to support the patient in motion concerning the ability to perceive, use, control, take care of and use his or her body in suitable ways considering the demands from the physical and social environment (LSR 1997).

Physiotherapy enhances health through movement, treatment and rehabilitation. In physiotherapy theory, body and mind are considered inseparable (75, 76). Many treatment modalities in physiotherapy aim to affect both body and mind. The modalities include exercise, basic body awareness therapy (Basic BAT) (75), patient education and relaxation. As in rehabilitation research, physiotherapy research has seldom focused on social perspectives such as gender, class or ethnicity (55).

Physiotherapy is the most common non-pharmacological modality to which patients with FM are referred. The course of FM is affected by physical, psychological and social circumstances, and one needs therefore to consider all these when planning treatment and rehabilitation.

These patients gain most from multiprofessional programmes (38, 77, 78, 79, 80) that include physical conditioning and education. Physiotherapy therefore plays an important part in rehabilitation for women with FM.

Physical conditioning

Among physiotherapy treatments for patients with FM, physical conditioning in different forms is the one most often evaluated and which also shows the best, although somewhat contradictory, results (81). The effects of aerobic exercise in FM are evaluated in numerous studies (79) investigating aerobic exercise of different intensities, in warm-water pools, on land, as walking or swimming, as strength training and as flexibility training. Training in a warm-water pool is well tolerated and often preferred by patients (82). A meta-analysis (83) summarising the efficacy of aerobic exercises for patients with FM found evidence of positive effects of aerobic exercise programmes. As a result of physical exercise, patients improve in aerobic capacity, pain distribution, reduced pain-ratings and tender-points scores (84, 85, 86), physical functioning, self-efficacy and tenderness (82, 87). In other studies, walking (87, 88) and pool exercise in warm water (82, 89, 90) are shown to improve function and well-being and to reduce symptom severity.

Exercise also affects mood and depression positively (88, 91).

Not all studies show positive gains from exercise therapy and of those that do, the dropout rate reaches 40% in some. The reason for dropping out is often exercise-induced pain.

Optimal intensity of the exercise programme and individual adjustments are important if high compliance is to be reached without negative side-effect symptoms (92).

The exercise programme should be applied individually, account taken of the particular muscular dysfunctions, the autonomic nervous system and pain-processing seen in patients with FM (92). In an article reviewing physical exercise in FM, Mannerkorpi and Iversen (81) conclude that patients may improve their aerobic capacity and physical functioning, and diminish their tenderness, with moderate exercise twice weekly. The exercise programme should last at least 20 minutes and be at a sufficient intensity, at least 55% of predicted maximum heart rate.

Pain alleviation using e.g. acupuncture, transcutaneous electric nerve stimulation (TENS) and local heat usually help patients with FM, giving short-term pain relief (51).

Basic Body Awareness Therapy (Basic BAT) is a physiotherapeutic treatment modality frequently used in the Nordic countries in e.g. pain rehabilitation (93, 94, 95, 96, 97, [Study I] 98).

Basic BAT was developed by the Swedish physiotherapist Roxendahl, with strong influences from her meetings with the French psychotherapist and movement teacher Jacques Drosby. In Basic BAT (75), basic movements, breathing and mental awareness are used to restore balance and freedom of movement, emphasising the resources of the body and mind as a whole. Patients are taught to attend both to how the movements are performed and what they experience during performance. This is claimed to stimulate mental presence, to be in reality, and to increase awareness of the strengths and limitations of one's own body.

Roxendahl (75) developed theories of the body ego, which she defined as the bodily aspect of the unity body/mind that is the human being. In this holistic view, the physiotherapy treatment situation contains four important parts: interaction between the patient and the

physiotherapist, the patient's motivation, the patient's consciousness as a human being and the practice of movements in the concept of Basic BAT. The interaction between patient and physiotherapist is an important part of the treatment concept (99).

A few studies (94, 96, 97[Study I], 98, 100) evaluate the effects of Basic BAT for patients with FM/CWMP. They indicate positive effects without reported negative side-effects; but larger, randomised studies are needed for evidence.

By training movement during mental awareness, postural control, breathing and muscular dysfunction are supposed to become normalized. Basic BAT aims at increasing mental awareness, the perception of movement patterns and the boundaries of the body (75). In a qualitative study (101) (study II) of what women with FM or CWMP had gained from a rehabilitation programme, the women described how Basic BAT had helped them to recognize their boundaries. By doing so, the women became able to set limits and improve their self-image.

Relaxation training

Relaxation training is commonly used in rehabilitation for patients with chronic pain conditions (102) for managing pain and insomnia. There is no consensus about what relaxation method is the best (e.g. progressive muscle relaxation, autogenous muscle relaxation or visual imagery). All appear to be equally useful modalities for learning to relax. For the present purposes, modified autogenous muscle relaxation was used.

EMG-biofeedback training

EMG-biofeedback training for patients with FM was evaluated with positive results in pain and psychological parameters (103). Buckelew et al. compared EMG-biofeedback only and exercise only with a combination of both (87). The combination showed the best results.

AIMS

GENERAL AIM

The overall aim of the work presented in this thesis was to obtain further knowledge of the effects of multiprofessional rehabilitation programmes for women with fibromyalgia (FM) or chronic widespread musculoskeletal pain (CWMP) and to explore and obtain further knowledge of what strategies women with FM use and find successful in controlling their symptoms. The purpose was to further improve rehabilitation and thereby increase the possibilities for these women to live actively, to return to work and to continue working.

SPECIFIC AIMS

Specific aims were:

- to evaluate the effects of a twelve-week multidisciplinary rehabilitation programme, mainly emphasising physiotherapy, for women patients with either fibromyalgia syndrome or chronic, widespread, musculoskeletal pain,
- to describe and analyse how women with fibromyalgia or chronic, widespread, musculoskeletal pain, one year after completion, experienced a rehabilitation programme; and what knowledge and strategies they had gained,
- to explore, and obtain increased knowledge of, the strategies used by women working despite fibromyalgia regarding control of pain, fatigue and other symptoms,
- to investigate whether women patients with fibromyalgia are able to perform a work task and home care tasks with less muscle activity, recorded as surface EMG, after a rehabilitation programme than before the programme, and
- to investigate whether pain intensity and perceived exertion can be affected in women patients with fibromyalgia after a rehabilitation programme compared to before the programme.

METHODS AND SUBJECTS/PARTICIPANTS

COMBINATION OF QUALITATIVE AND QUANTITATIVE METHODS

The present study design combines qualitative and quantitative methods in an emergent design, both being equally important for the results. The combination can be used in different ways (104, 105): the choice of method was guided by the research questions. New research questions arose as others were answered, and the appropriate method for elucidating each question was chosen. A qualitative approach was chosen as suitable in a field such as the present one where no or little knowledge was available, and where it was desired to explore the women's experience and strategies. It was important to listen to the women themselves, who are living with the complaints, and to speak on their behalf since they often have difficulties in making themselves heard.

STUDY SETTINGS

Intervention programmes

Rehabilitation programme I (Studies I and II)

The rehabilitation programme in studies I and II took place at a rehabilitation centre in a city in southern Norrland. This is a rural area, sparsely populated with a traditionally high level of unemployment. The programme lasted 12 weeks with 13 days at the clinic, starting intensively with three days a week during the first three weeks, and then single days on every other week during the next nine weeks. When the rehabilitation period was completed, the patient, the employer, the local social insurance officer and the rehabilitation team members met and discussed plans. Three months later the patient attended a three-day follow-up, which ended with a final meeting with the same participants. The aim of the programme had been to provide the patients with adequate knowledge of FM and CWMP, and if possible help them to see the pain in a more understandable context. The programme was designed to enable them to cope with pain, fatigue and stressful situations and to help them feel active, resourceful and competent in their own rehabilitation. The programme consisted of education, group discussions, physical training and individual guidance. During the programme the patients were urged to continue their exercises and to apply the coping strategies they had learned even after the programme. This was assumed to improve the women's work ability and their quality of life.

The education and group discussions focused on pain, stress, coping, working situations, medication and how to improve the quality of sleep. The link between emotions and bodily reactions was often highlighted, explained and discussed by all the team members. The physiotherapists provided Basic BAT (75), relaxation training and fitness training in a warm-water pool. The relaxation training used a modified autogenous muscle relaxation technique. The fitness training in a warm-water pool was moderately intensive, guided and to music. All the women followed individual programmes for walking and stretching. This was continually evaluated and improved. The physiotherapists also introduced pain-relieving methods such as TENS, heat and acupuncture. The individual guidance by the trained social workers was aimed at supporting the patient in finding new coping strategies.

The rehabilitation team consisted of a physician specialising in rheumatology, a registered nurse, two physiotherapists and two trained social workers. The physician examined the participants before they entered the programme and was available if medical consultation was needed during its implementation. The registered nurse administered the course as well as contacts with employers and social insurance offices. She took part in the teaching and the

group discussions, as did the physiotherapists. The trained social workers offered the participants individual, supportive guidance. All the team members had earlier experience of chronic pain management.

Rehabilitation programme 2 (study IV)

The rehabilitation programme evaluated in study IV was conducted in Stockholm, Sweden's capital and largest urban area. Part one was individually designed, part two was four weeks of group rehabilitation.

The length and content of part one were established together by the patient and the team, according to the former's needs and possibilities. During this part, the patients spent about six hours a week at the clinic. The length varied between two and eight-and-a-half months, depending on individual needs and progress. If the treatment period lasted over the summer, it included a two-month break.

Part one consisted of group training in basic BAT (75) and relaxation once a week, a five-course of weekly lectures with information about pain and stress mechanisms, sleep, nutrition, ergonomics, social benefits and medication. There were also five weekly discussion group meetings and a workplace visit. The patients learned to decrease and control their muscle activity through basic BAT, relaxation training, and work training with EMG-biofeedback (87) during work in situations as close as possible to reality. With basic BAT, the patients learned to be aware of how they used their bodies and how they could improve, find position and balance, avoid unnecessary muscle tension and prevent deterioration. Training with EMG-biofeedback gave direct feedback on how they activated their muscles during work training. This training employed an AT33 Autogenic System or an M57 J&J, both from the Biofeedback Institute in Göteborg, Sweden. EMG-biofeedback training for patients with FM has been evaluated previously regarding clinical symptoms, sensory and affective pain components and quality of life (87, 103). However, no one has yet investigated whether muscle activity during activity decreases after such training in patients with FM.

Part two of the rehabilitation programme, intensive rehabilitation for four weeks, started when the team and patient estimated that the latter had regained 25-50% of work ability. This aimed at preparing the patient for the demands of her workplace. Patients spent about 20 hours a week at the clinic.

During the four weeks, the patients continued work training, now in groups, with EMG-biofeedback. The body awareness training focused on body positions needed at work, the discussion group continued with the same themes, but in greater depth. Training in a warm-water pool and walking were again included. After the programme the patients were expected to start work training slowly, often two hours a day or less, and then increase slowly. When needed, a meeting for planning work training and return was held with the patient, the team, the employer and an officer from the local social insurance office.

The rehabilitation team now consisted of a physician specialising in rehabilitation medicine, a nurse, one or two physiotherapists, an occupational therapist, a trained social worker and a psychologist. All team members gave lectures, the social worker and the nurse led the discussion groups, the physiotherapist provided the physical exercises and the Basic BAT and the occupational therapist provided the work training with EMG-biofeedback.

OVERVIEW OF METHODS

An overview of methods used in the present thesis is presented in table 1.

Table 1. Overview of methods used in the four studies.

Study	I Quantitative	II Qualitative	III Qualitative	IV Quantitative
Research question	What are the effects of a 12 week multi-professional rehabilitation programme for women with FM or CWMP ?	How did women with FM or CWMP experience a rehabilitation programme? What did they gain from the programme?	What strategies do women working despite FM use to control pain, fatigue and other symptoms?	Are patients with FM able to perform work tasks and home care tasks with less muscle activity after a rehabilitation programme than before, and compared to healthy controls? If so, do the changes coincide with their reported subjective experience?
Study design	Prospective, non-randomised intervention trial. 43 women consecutively assigned to a treatment group (n=23) or waiting-list control group (n=20).	Exploratory and analytical. Semi-structured individual interviews with 16 women from the treatment group (study I) at 15-month follow-up.	Exploratory and analytical, emergent design. 12 women working despite FM participated. Data collection with diaries, focus group discussions (FGD) and individual interviews.	Prospective, non-randomised intervention trial. S-EMG recorded during four tasks, in 16 women with FM before and after rehabilitation and in 10 healthy women with the same time interval
Methods	Measurements at study entry, after 3 and 6 months. Follow-up in treatment group also after 15 months. Comparisons of movement quality (BAS-H), pain dispersion (pain drawing), pain intensity (VAS), quality of life (QLS) and consequences of pain (MPI).	Women interviewed one year after rehab programme about what they remembered from programme: what was useful and how this helped them them. Interviews analysed according to constant comparisons method in “grounded theory”.	Women wrote diaries about how they managed their problems. Diaries analysed with content analysis. Themes discussed and elaborated during FGDs. New and some “old” themes needed deepening. Interviews conducted to reach saturation. FGDs and interviews analysed according to “grounded theory”. Final model integrates the two stages of the results.	Muscle activity in trapezius bilaterally, infraspinatus and extensor digitorum, dominant side, measured with S-EMG during one work task and three domestic tasks. Pain intensity and perceived exertion measured after every task with Borg CR-100 scale. EMG analysed as μ V and relative % of sub-maximal reference contractions.

SUBJECTS/PARTICIPANTS

Background data on the subjects/participants, all women, is presented in table 2. In studies I and II, both diagnoses FM and CWMP were included, due to the referral system. In studies III and IV only women with FM participated, following the inclusion criteria for the rehabilitation programme.

Table 2. Background data on subjects/participants.

Study	I	II	III	IV
Subject/participant, n	43	16	12	26
treatment/control, n	23/20			16/10
Age, mean (range)	45 (23-59)	45 (25-59)*	50	35 (25-47)
Diagnosis, n				
FM	25	7*	12	13
CWMP	18	9*		
healthy				10
Years with symptoms, mean (range)	13 (2-39)	13 (2-20)*	6-8 years after rehabilitation*	6 (1-20)

*Corrected figures compared with text in paper II page 98.

**The women had participated in a rehabilitation programme 6-8 years earlier, when they already had the diagnosis FM.

Work Situation

The subjects'/participants' work situation on rehabilitation entry is summarised in table 3.

Table 3. Summary of subjects'/participants' working situations.

Study	I n	II n	III* n	IV n
No sickness absence	10	4	2	1
25-75% sickness absence	13	5	10	4
100% sickness absence				
<1 year	3	3	0	5
1-11 year	17	4	0	6

*At study entry

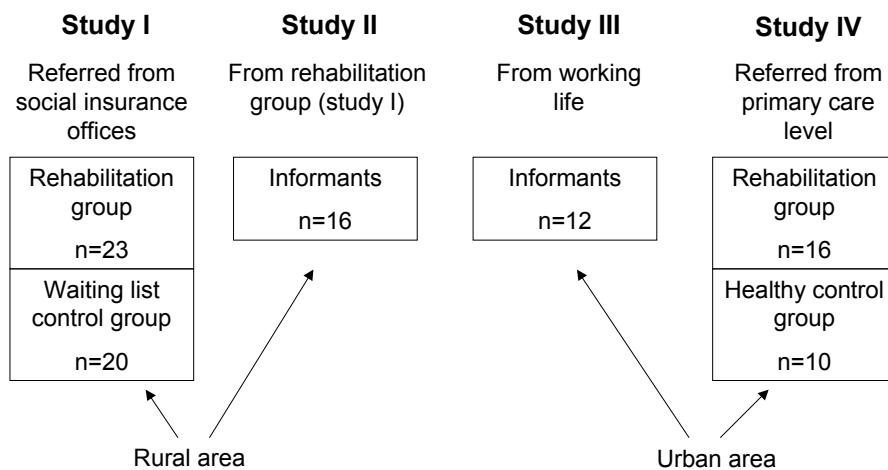


Fig 1. Overview of patients and participants, source of referrals.

DROPOUTS

Study I

Forty-three (23 treatment group, 20 waiting-list control group) women participated in assessment I. Forty-one (93%) (21 treatment group, 20 waiting-list control group) women participated in assessments II and III, and 18 (75%) women of the treatment group participated in assessment IV. Reasons for dropping out were hampering medical conditions, change of residence and inability or unwillingness to participate in the follow-up evaluations.

Study II

Of 18 women asked to participate in the interview study, two were unwilling to participate.

Study III

Twenty women were asked to participate in the qualitative study. Eight declined for medical reasons, lack of time, change of residence, inability to take time off from work or the wish not to think about FM.

METHODS

The study design is summarised in table 1: below follow more details.

Study I, "Effects of a rehabilitation programme"

The design was a prospective, non-randomised intervention trial. Inclusion criteria were: diagnosed FM according to the ACR-90 criteria, or CWMP, well-analysed pain not owing to injury or other diseases, no drug abuse or serious psychiatric disease; considered by the social insurance office to need rehabilitation for return to work. Forty-three women with FM or CWMP, who were referred for rehabilitation, were assigned consecutively to two groups: 23 to a treatment group and 20 to a waiting-list control group. Data were collected with self-administered questionnaires (MPI, QLS), VAS and pain drawings, and BAS-H. The latter is a structured test of everyday movement, where the physiotherapist observes the patient's ability, pattern of motion and general behaviour. Data was collected on four occasions for the

treatment group: before treatment; after three months when the treatment period was finished; at the three-month follow-up six months after first data collection, and at a one-year follow-up 15 months after first data collection. The waiting-list control group were assessed three times: base-line assessment, after three months and after six months. The same physiotherapist assessed the patients' movement ability and quality of movement behaviour with the BAS-H on the same occasions as the self-administered questionnaires were filled in.

When the first study was planned, we were aware that rehabilitation affects biopsychosocial aspects that are difficult to assess with questionnaires. A qualitative interview study was planned to explore these complex interactions. The qualitative approach was viewed as suitable as it is a way to explore unknown personal experience, interpretations, perceptions and strategies.

Study II, "Experience and gains from a rehabilitation programme"

Study II was designed as a qualitative, exploratory and analytical study. Sixteen of the 18 women with FM or CWMP from the study I treatment group, who participated in the one-year follow-up, agreed to and participated in the interview study.

The women's experience of the rehabilitation, what they had gained and how this had affected them were studied through semi-structured, individual interviews. The women were asked how they had experienced the programme, what they remembered and what knowledge they had gained from it. The interviews were tape-recorded and transcribed verbatim.

The results of the second study raised new questions. It was obvious that living with FM/CWMP is difficult, to remain working even more difficult. How did the women who kept on working despite FM/CWMP manage?

Another qualitative study was initiated to further explore this phenomenon.

Study III "Strategies used by women working despite FM"

Study III was a qualitative, exploratory and analytical study with an emergent design. The kinds of strategy the 12 informants used for managing their situation at home and at work were studied. The women had participated in rehabilitation programmes six to eight years before the study: they stated that they had been working or studying during the previous year. Data was collected with diaries, focus group discussions (FGDs) and individual, thematised interviews. Themes from the diaries were further elaborated in the FGDs. New themes from the FGDs and themes from the diaries that needed further elaboration in order to be saturated, were explored in the interviews. The FGDs and interviews were tape-recorded and relevant parts were transcribed.

The results from studies I – III revealed that increased body awareness was an important part of managing and improving FM symptoms. The women in the first study demonstrated improved quality of movement measured with BAS-H. The second and third studies showed how important body awareness was. It helped them to feel what they benefited from and helped them to manage the changes necessary to increase their well-being.

The fourth study examined whether this increased body awareness was measurable quantitatively. Did the patients learn and use a more functional movement pattern? If so, were the changes measurable? Did the changes affect the subjective experience of pain and exertion? To investigate this, an EMG study was carried out.

Study IV “Changes in muscle activity after a rehabilitation programme”.

Study IV was a prospective, non-randomised intervention trial including a healthy control group. Sixteen women with FM who had participated in an individually adjusted rehabilitation programme for women with FM, were consecutively assigned to the study. Ten healthy, age-matched women served as the control group and were measured in the same way. Muscle activity in trapezius pars descendens bilaterally, and in infraspinatus and extensor digitorum on the dominant side, was measured with S-EMG in one work task and three domestic tasks. Pain intensity and perceived exertion were assessed on the Borg CR-100 after every task. The patients with FM were measured before and after a rehabilitation programme for women with FM, the healthy controls being measured at the same times.

QUANTITATIVE RESEARCH METHODS

Self-administered questionnaires

Pain drawing (*study I*) involves the patient in marking on a drawing of a woman all body parts where she feels pain at the time. The drawings were scored for the presence or absence of pain in each of 45 body areas, weighted according to the percentage of body surface that each area covered (106).

The Visual Analogue Scale (VAS) (*study I*) is a continuous scale of 100 mm with the extremities "no pain" and "intolerable pain" (107). The VAS is commonly used both in acute and chronic pain conditions. In the present study three VAS were used at each examination: pain at the time the form was filled in (VAS 1), the least pain felt during the previous week (VAS 2), and the worst pain felt during the previous week (VAS 3).

The Quality of Life Scale (QLS) (*study I*) is a 16-item scale with a 1 - 7 point rating scale (1 = terrible and 7 = delighted). Each item includes an important domain of life. The scores of each item are summed to a total life satisfaction score, ranging from 15 to 105. The scale has been validated and tested for populations with chronic illness (108).

The Multidimensional Pain Inventory (MPI) (*study I*) is a self-administered questionnaire that measures psychological, social and behavioural aspects of chronic pain. The instrument has been validated (109). It comprises 13 items on a 0 - 6 rating scale, forming three sections. Part one assesses patients' chronic pain. Part two assess how significant others respond to their displays of pain. In part three patients rated the frequency with which they performed common, everyday activities.

The Borg CR-100 scale (*study IV*)

Pain intensity and perceived exertion after each activity were assessed on Borg Category Rating (CR)-100 scales.

The Borg CR-100 scale is a further elaboration of the validated Borg CR-10 scale (110), and describes the subjective level of symptoms. Their reliability and validity are good. The Borg CR-100 scale varies from 0 – "Nothing at all" – to an indefinite value above 120 – "Absolute maximum". "Hardly noticeable" corresponds to 2 on the scale and is the threshold of what is perceivable. "Very strong" corresponds to 70.

The BAS-H

The body awareness scale-Health (BAS-H) (*study I*) is used by physiotherapists observing the patients' ability and patterns of motion and breathing and general behaviour (75). Twenty-one items are rated and scored on a seven-grade scale. The items are summarised into four sub-indices: grounding/centre-line index (10 items); centring of movement /breathing index (4 items); flow index (8 items) and additional items (3 items). The additional items were not assessed in the present study. Validity studies have investigated the criterion and construct validity of BAS-H (100, 111)Validity was in accordance with theoretical expectations. The scale seems to be a reliable assessment (93) and shows responsiveness to change (111) in rehabilitation outcomes for patients with prolonged pain.

The Body Awareness Scale (BAS) rates a structured interview based on the comprehensive psychopathological scale (CPRS) (112). Roxendahl modified the scale, including some body-oriented questions (75). The scale comprises 20 items, scored from 0-3 in 7 steps. Using BAS-H, the examiner freely chooses interview questions from the BAS to suit the current group of patients. In this study questions concerning pain, fatigue and vegetative disturbances were chosen.

The validity and reliability of the BAS in psychiatric care have been demonstrated by Roxendal (75).

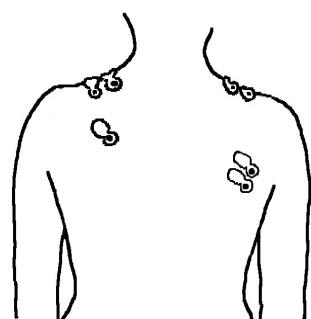
Surface Electromyography (S-EMG)

S-EMG was recorded from trapezius pars descendens bilaterally, and from infraspinatus and extensor digitorum on the dominant side. These muscles were chosen since they were estimated to be active during the tasks tested and could hypothetically be affected by training in body awareness and EMG-biofeedback.

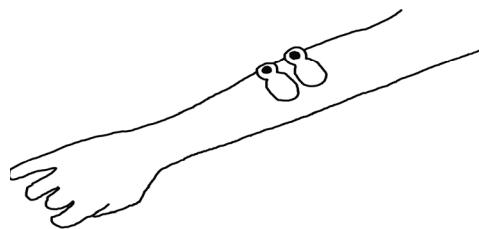
Electrode placement

To allow comparisons between the first and second occasions of S-EMG measurements, the electrode placement was standardized and followed the SENIAM recommendations (113). Inter-electrode resistance was measured and only values below 10 kΩ were accepted.

The earth electrode was placed at the upper-medial angle of scapula and the four pairs of electrodes were placed as demonstrated in figure 2a-b:



2a



2b

Figure 2a. Placement of three pairs of electrodes on the trapezius, pars descendens bilaterally and on infraspinatus on dominant side. Earth electrode (single) placed over upper, medial part of scapula.

Figure2b. Electrode placement on the extensor digitorum.

First a recording at rest was made, then recordings were made during four tasks: writing a text on a computer, pouring water into five glasses, ironing a shirt and vacuuming.

While writing on a computer and ironing a shirt, EMG was recorded for every second 15-s-period six times for 3 minutes, starting after 15 s. A sample of 10 s was analysed from every 15-s-period and a mean of every period was calculated.

The whole movement sequence during pouring water into five glasses was EMG-recorded. A phase of 10 s in the middle of the whole period was used for calculating the mean.

The whole movement sequence during vacuum cleaning was EMG-recorded. Sampling for the analyses was done in two parts, while vacuuming a carpet *in front* of two chairs (1 minute) and while vacuuming a carpet *under* the chairs (1 minute). A sample of 10 s was analysed from every second 15-s-period, a mean of every period being calculated.

Muscle activity during the dynamic physical tasks described was analysed. The raw EMG signals were rectified and filtered. Means of the time periods selected were calculated. The calculated results were shown in two ways. 1) μ V: recorded during the task, used without comparison to any reference contraction, and 2) %subrefEMG: μ V during the task divided by the μ V recorded during the sub-maximal reference contraction described above.

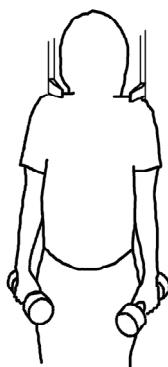
Sub-maximal reference contractions

Since the patients with easily-elicited pain could not perform maximum test contractions without increasing pain level, standardized sub-maximal reference contractions were designed.

For trapezius pars descendens, infraspinatus and extensor digitorum the patient initially sat on a stool, holding a one-kilo weight in each hand. The upper arms were abducted 45 degrees in the scapular plane, the elbows flexed 90 degrees and the wrists extended. The subject kept this position for 5 s, rested for 10 s, and repeated the sequence once. The author stood behind the subject, ensuring the right degree of shoulder abduction.

The experimental procedures were examined after measuring five patients in this mode whereupon it was assessed that the sub-maximal tests needed slight modification. In the eleven following patients and the ten pain-free subjects the new protocol, as described below, was used. In each case the same protocol was used on the second occasion.

For trapezius pars descendens the height of the midpoint of trapezius pars descendens was measured bilaterally (fig 3a). The pointers were then raised 5 cm on each side. Holding a 5-kg-weight in each hand the subject was instructed to lift the shoulders until they touched the pointers. The subject kept the shoulders raised for 5 s, rested during 10 s and then repeated the procedure a second time.



3a



3b

Figure 3a. Sub-maximal reference contraction of the trapezius pars descendens.

Figure 3b. Sub-maximal reference contraction of infraspinatus.

For infraspinatus the upper arm was positioned in the plane of scapula, with 50 degrees shoulder flexion in that plane (forward-and-slightly-outward). The elbow was flexed 90 degrees (fig 3b). The subject held a 1-kg-weight and was instructed to raise the arm a few cm above the table by increasing abduction. She was to hold the arm there for 5 s, rest on the table for 10 s and then repeat the procedure once more.

For the extensor digitorum the subject was instructed to hold the forearm down on the table and lift the 1-kg weight only by extending the wrist enough for the weight to be above the table surface, hold it there for 5 s, rest for 10 s and then repeat the procedure once.

The physiotherapist (ML) stood next to the subject during all reference contractions to give instructions and to ensure compliance.

Tasks

The *computer task* was to write a text for three minutes (fig 4a), shown in the copyholder. The subjects were told not to worry about spelling or mistakes.

In the *second task* the glasses were marked one to five (fig 4b), the instruction being to fill them in the marked order at the subject's own pace.

The *third task* was to iron a man's shirt (fig 4c) for three minutes.

The *fourth task* was to vacuum-clean a carpet for two minutes. The subject had to start by vacuuming an area in front of two chairs for 75 s and, when told, under the first chair for 15 s, again in front of both chairs for 15 s and finally under the second chair for 15 s. During the vacuum cleaning, confetti was continuously spread on the carpets.

After the tasks, the subjects rested and relaxed for two minutes. At the end, rest was EMG-recorded in the same way as before the test activities.

On the second measurement occasion, the chair, table and ironing board were set at the same height as the first time. Subjects were encouraged change the height to be more comfortable if they wished, since this was considered part of their new behaviour and knowledge.

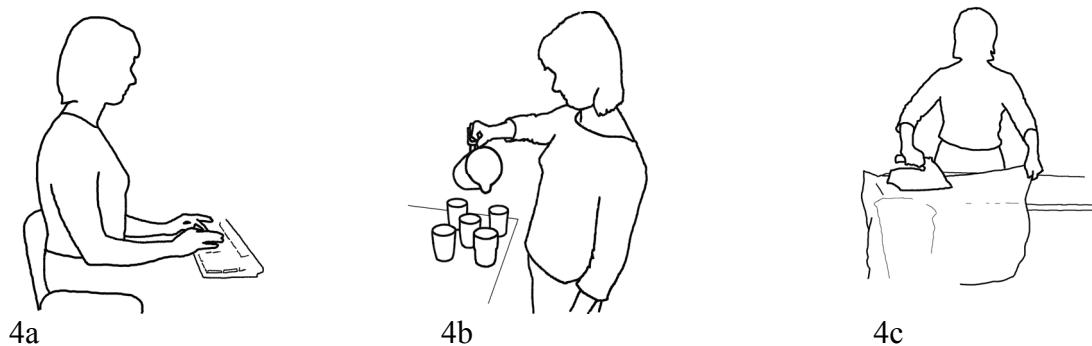


Figure 4a. Task: writing on a computer.

Figure 4b. Task: pouring water in 5 glasses and placing glasses on tray.

Figure 4c. Task: ironing a man's shirt

EMG recording

Surface electromyography (S-EMG) was recorded bipolarly with disposable electrodes (pre-gelled disposal Blue Sensor, N-00-S, Ambu AB, Sweden) connected by wires to four of the channels of an electromyography measuring system (Myosystem 2008, Noraxon, Neurodata GmbH, Vienna). The software used was MyoResearch 98 (Neurodata GmbH, Vienna).

Sampling frequency was 1000 Hz. After rectification a six-pole Butterworth filter was used (b6x1000.flt).

The experiment consisted of ten stages: a baseline pre-performances rest phase, sitting resting at the computer, writing on the computer, a rest standing at the desk, pouring water into five glasses, a rest standing at the ironing table, a phase ironing a shirt, a standing rest with the vacuum cleaner, vacuuming and a post-exercise lying-prone rest.

Resting values

During resting EMG was recorded for 15 s before each task, 5 s were used for calculating means. The lowest mean value from any rest position was subtracted from sub-maximal reference contractions and tasks.

Reference contractions

In the reference contraction phases, EMG was recorded for five seconds and a mean value of the contraction was calculated for the middle 3 seconds of the 5.

EMG analysis

Muscle activity during the dynamic physical tasks described was analysed. The raw EMG signals were rectified and filtered. Means of the time periods selected were calculated. The results were calculated and demonstrated in two ways: 1) μV : recorded during the task and used without comparison with any reference contractions, and 2) $\% \text{ subref EMG}$: μV during the task divided by μV recorded during the sub-maximal reference contraction described above.

STATISTICS

In all four studies, descriptive statistics were used to present demographic data. For non-parametric data, in studies I and IV, Friedman's ANOVA by Ranks were used to test between-group differences. Within-group differences were tested with Wilcoxon. To further investigate differences found in quality of movement, measured with the body awareness scale-health (BAS-H) in study I, non-parametric rank-invariant methods developed by Svensson (114, 115) were used.

Study I

All statistics were performed using the SPSS (version 9.0) for Windows statistical package. To investigate differences within the groups after the programme (I-II), at three months follow-up (I-II-III) and within the treatment group at one-year follow-up (I-II-III-IV), Friedman's ANOVA by ranks, a nonparametric test for several dependent samples (overall) was conducted for the BAS-H, the VAS, the MPI and the QLS. Mann-Whitney U tests were conducted to investigate differences in the pain drawing. Friedman's Anova by ranks for two dependent samples were conducted for the VAS, the MPI, the QLS and the pain drawing (I-III) (I-IV). To further investigate differences found in the BAS-H, non-parametric rank-invariant methods developed by Svensson (114) were used. The methods are valid for all

types of ordered data without assumptions regarding distribution (115). The overall systematic change in the values of the BAS-H was evaluated by analysing the change in the distribution of individuals on the BAS-H on the different assessment occasions. A change in marginal distribution indicated a systematic change over time in the BAS-H levels for the group. This can be illustrated by plotting the two sets of cumulative relative frequencies for the marginal distribution against each other, yielding a relative/receiver operating characteristic (ROC) curve. A systematic curve towards a lower value in the ratings of BAS-H will result in an ROC curve that deviates over the diagonal of unchanged distribution. The greater the deviation, the stronger the systematic change between the two occasions.

Accordingly, an improvement in BAS-H will give an ROC curve above the diagonal (115). The empirical measure of the systematic shift in position between the two occasions is called relative position (RP). Possible RP values are in the interval -1 to 1. A value of RP close to zero indicates unchanged distribution of values over time for the group. Decreasing BAS-H level, which means a more functional pattern of motion at the second measurement, implies a negative RP value, and the corresponding ROC curve will deviate from the main diagonal in the upper direction.

Study IV

All statistics were performed using the SPSS (version 13.0) for Windows statistical package. $P \leq 0.05$ was considered a statistically significant difference, $p = 0.051 - 0.10$ was considered to be a tendency towards a difference.

Mann Whitney's U-test was used for differences between the groups and Wilcoxon's signed ranks test for differences within the groups. Since the EMG data was not normally distributed, non-parametric tests were used. Perceived pain intensity was very close to zero in all controls, for which reason no statistical comparison was made between groups or within the control group. Within-group comparisons of pain intensity employed the Wilcoxon signed ranks test. Perceived exertion was very low in the controls and no comparison was made between them and the patients. Within-group comparisons of perceived exertion in the patients were done with the Wilcoxon signed ranks test.

QUALITATIVE RESEARCH METHODS

Qualitative methodology is not only a question of what research methods are used; it also comprises a specific perspective on research which goes beyond the techniques used.

Qualitative methods are still uncommon, but increasing in medical research.

The perspective of qualitative research covers some basic assumptions about the world. One is that realities are subjective, socially constructed and multiple i.e. *the ontological assumption*. Therefore a holistic research approach is preferred, where phenomena under study are interpreted within their context. A qualitative study does not have a preconceived theory that is tested; but allows the theory to emerge from systematic data analysis. The holistic approach also implies that researcher and informant always interact and influence each other. This is the second assumption—*the epistemological assumption* (116). Qualitative research methods aim at understanding the research question from the perspective of the being studied, rather than studying statistical causation (105). Finally, the *axiological assumptions* are that research is value-bound, and that the researcher has pre-understandings, expectations and biases which influence the research and have to be conscious and debated (14, 117).

The many different methods have in common that they do not deal with numbers (118). Qualitative research methods differs from quantitative in that, for example, the samples are

small and non-probalistic (non-randomised). Non-probalistic sampling includes about 15 techniques (119).

Qualitative methods are especially suitable in areas where we have no or little previous knowledge, where the phenomenon has to be explored. Inductive reasoning is often used, the research starting in and from the data. The process aims at formulating a model or a theory. It is therefore impossible to specify the research design beforehand: the design is adapted as the research progresses; it is emergent. Research in rehabilitation has so far mostly lacked this perspective, as qualitative methods are seldom used (105). Yet qualitative research has many applications in rehabilitation research: improving rehabilitation by considering relatives' and patients' perspectives, extending professionals' understanding of patients' perception of disability, recovery and chronic illness, and contributing to the development of new evaluation models (105).

In the present work the qualitative methods grounded theory and content analysis were used.

Grounded theory

The grounded theory method of constant comparisons was the main qualitative tool used in this work. Grounded theory was developed by Glaser and Strauss in the 1960s (120).

The theory seeks to describe the field studied, and also to develop new theoretical models instead of using pre-conceived specific theoretical frameworks during the analyses of data. By building theories, or models, the results are made theoretically generalizable to other, similar situations. This contrasts with other, more descriptive, qualitative methods, for instance content analysis where the voices of the informants are in focus (116 page 12, 121). Various data collection methods such as interviews, observations and written material can be used. Grounded theory is regarded as suitable for obtaining new knowledge, where concepts are generated about everyday events, thoughts, beliefs, norms etc. It includes all stages in research, from formulating the research question through sampling procedures, data collection and analysis to the final development of concepts, models or theories. Data analysis involves a coding procedure where the data is often text. Thereafter comes conceptualising and classifying the codes, forming categories (121) and finally building a model or a theory (table 4). Closeness to the data is stressed, the researcher constantly commutes back to and compares codes, categories and models with the original data in the technique known as constant comparisons. Data collection and analyses are parallel processes, where new knowledge from the analyses is used in data collection.

Table 4. shows different levels of abstraction in data interpretation data during the analysis process in grounded theory (example from study III).

Interview quotation (concrete level)	Open codes (descriptive interpretation)	Categories (abstract level)	Generated theory (generalised level)
“...deteriorate if I rest, my muscles have to be sufficiently active all the time. Take a walk with the dog, ...when I wake up in the mornings I sometimes have a lot of pain. Out with the dog, regardless of the weather, then the body gets going. It is like a struggle between my own will and the pain, every morning when the pain is bad. Then there are the good mornings.....”	motion body awareness knowledge struggle	take care of oneself knowledgeable struggle	Living with FM is a constant struggle not to be overwhelmed by the pain.
“..yes, I have tried this with pain medicine of all kinds, but they don't help. If I can rest immediately it is as effective...”	refrain medication rest in time	pain as guide	
“..not to deny the pain, but also not to worry about the pain at all times of the day, One should not be afraid of the pain, so one can't do anything, then you get handicapped”.	recognize the pain refrain from medication not letting pain rule		

Content analysis

Content analysis is a method with two variants. One deals with objective, systematic and quantitative description of communication – quantitative content analysis. The other, used in study III, includes interpretations of the manifest and latent content, underlying meaning and is referred to as qualitative content analysis (122). In qualitative content analysis, the text is first divided into units of meaning. These are condensed into descriptions close to the text, and the latent content is interpreted. The method was used in study III to extract important themes and strategies from diaries recounting how the women managed their symptoms at home and at work. The main difference between content analysis and grounded theory is that in the former the analyses are close to the text and do not aim at generating models or theories.

Data collection methods

Thematised and semi-structured interviews (studies II and III)

An interview is an interaction between two people, where they influence each other. Respect and mutuality are important characteristics (117). The aim of the interview is to obtain subjective descriptions of the interviewee, to interpret the phenomena described (117). A thematised interview has open questions about themes, decided upon beforehand. The interviewer has to be flexible and ask follow-up questions to clarify and expand what is said. This is important both to get the richest possible data, but also to ensure credibility, that the data have high quality and that as many aspects as possible are captured.

In study II the interviews were semi-structured. They were quite short and followed a precise interview guide. In study III they were thematised, with more open questions and probings, aiming at exploring the phenomenon in depth.

Diaries (study III)

Diaries are often used as a source for qualitative analysis. They are regarded as suitable for capturing personal reflections, experience and ideas (123).

The present informants were instructed to write diaries over two weeks, at least five days a week. They were to write about what they did to manage their lives – with actions, thoughts and wishes. They chose whether to write by hand in an exercise book, or on the computer.

Focus group discussions (FGD) (study III)

Focus group discussions (FGD) are used to gather information about perceptions and ideas on norms, values and attitudes in groups or sub-group cultures (124). They can e.g. supplement other methods to compare individual experience with group experience (116). In the present work, the FGDs were performed in a room at the university, with a moderator (ML) and an assistant moderator (AO). In FGDs it is important to create a comfortable and productive atmosphere. The questions elaborated the themes and strategies from the diaries. The moderator has to be well-informed in the subject and skilful in keeping focus and developing questions (116). He or she also has to encourage everyone to talk and allow everyone to be heard. An assistant moderator is useful, both to help in probing and to operate the tape recorder. Relevant parts of the FGD tapes were recorded and transcribed verbatim.

Qualitative analyses

Semi-structured interviews (study II)

The transcripts were read through several times to get an overall impression. The texts were imported into the “Open Code” program (free download from Umeå University, Department of Epidemiology), and analysed in accordance with grounded theory constant comparison (120, 121). The analysis was performed in three steps. In the open coding procedure two researchers coded in parallel. The codes were then compared and discussed until both could agree. During the continued analysis all three researchers participated. The open codes were compared and grouped into five categories. Their properties and dimensions were specified and analysed by returning to the original data. In the third step the categories were assembled into a model.

Diaries (study III)

The diaries were carefully read, the most important parts being summarised and coded separately by two of the researchers to describe different strategies used by the women (table 5). The most striking theme was how “every day was a struggle” for the women; to live a decent life, against the FM consequences, but also against prejudice. Other themes were grief for the parts of life that could not be lived, loss of a functioning body, anger at the pain, vulnerability in relation to family, friends, colleagues and health-care staff. As a second step the codes were compared and negotiated until both coders agreed. The codes and themes were used as a guide for the focus group discussions.

Table 5. Strategies used to manage the symptoms, as described in the diaries.

Strategies
Slow tempo
Split activities
Prioritise, plan
Rest
Various forms of heat
Exercise, keep fit
Perceive signals from the body and respect them
‘The pain is not dangerous’
Positive thoughts
Enjoy life as much as possible
Positive view of life
Unwillingness to give in

Focus group discussions (FGD) (study III)

The tape recordings of the focus group discussions were listened to and important parts chosen and transcribed verbatim by the author. To survey the data, the transcriptions were independently read several times by two researchers. We especially observed new strategies or other themes that had not been discovered previously, but we also sought all aspects of the themes already identified. The FGDs were coded; the analysis continued according to grounded theory. Three researchers worked together to group codes together into categories and find connections between them. The previous codes were expanded and described more richly. A few major concepts became a part of the model at an early stage: struggle, grief, positive thinking, setting limits, being knowledgeable. These concepts became central categories and formed the basis for the continued analysis. During this phase it became obvious that some categories were not yet saturated. Also, new themes emerged, among them the strategy “pain as a guide”. To our knowledge, this strategy had not earlier been described. It was considered complex and in need of much skill. We therefore felt it important to elaborate it further. Interviews were planned to collect more information about this strategy, and about other themes such as “social support at work” and cooperation with the family”. Two of the women, who had demonstrated a reflective attitude and much knowledge during the FGDs, were interviewed.

Thematised research interviews (study III)

The transcribed interviews were coded and analysed together with the earlier material. The analyses according to grounded theory continued after each interview. The researchers questioned and discussed the emerging categories and model at several meetings during the analysis. After the interviews we considered that the material was saturated. The final model, where the results are presented, combined the content analyses of the diaries and the grounded-theory analyses of the FGDs and interviews.

Trustworthiness in qualitative research

In qualitative research, the concepts validity, reliability and generalisability are discussed as different aspects of trustworthiness (14). The rigour of trustworthiness is extensive and precise.

Credibility (truth value, internal validity) refers to the ability to produce credible research, to capture the multiple realities of those studied: can others see what we see?

Triangulation is a common method for assuring credibility, where the question is investigated from different angles. Different data sources, data collection methods, methods for analysing and researchers with different backgrounds, can be used in triangulation. Other examples of methods for assuring credibility are prolonged engagement and ‘members checking’ (returning the results to members of the studied group for checking).

Transferability (generalisability, applicability, external validity). In qualitative research it is given that the results are context- and time-bound. There are two ways of looking at transferability in qualitative research. One, is to provide the reader with a ‘thick description’, a description precise enough to enable the reader to decide whether the results are transferable (14). The other approach, sometimes called analytical generalisation and often advocated by epidemiologists, abstracts the results into hypotheses which can be transferred to similar situations and problems (117).

Dependability (consistency, reliability) Repeatability is not possible in qualitative research. Instead, dependability refers to the researcher’s ability to capture all aspects of the complex reality of those studied. The researcher has to provide audit trails, meaning that the research process has to be thoroughly described, all steps explained and possible to follow.

Neutrality In qualitative research, closeness between researcher and study participants is unavoidable and necessary for reaching high quality in the credibility. Here the term neutrality refers to neutrality of the data, not of the researcher. To achieve neutrality, the researcher has to ensure that the results and conclusions are grounded in data.

In the qualitative parts of the present work, several techniques were used to ensure trustworthiness.

In study II, triangulation was used. Three researchers from different fields: physiotherapy with special reference to pain treatment, medical sociology with special reference to gender research and rehabilitation medicine, collaborated on the analyses. As a physiotherapist with many years’ experience of rehabilitation for women with FM, I had prolonged involvement, which is considered important for the researcher to understand the field. My involvement may have been *too* extensive, the danger being that preconceived understandings would prevent me from perceiving other views than my own.

I used a thick description in the present report, where under ‘Locating myself’ I describe thoroughly my pre-understanding. I also did so under ‘Study settings’ and for all the steps in the studies .

In study III, triangulation was used at several contiguous levels in data collection: diary, FGD and individual interview, in the analysis: content analyses and grounded theory and in researchers: three from different fields. During the FGDs and the interviews, two researchers were always present, one as interviewer/moderator, the other as note-taker/co-moderator. Also in study III, my pre-understanding and earlier experience were both a strength and a problem, which was handled in the same way as in study II.

In the member checking, the members were mainly the same informants who participated in all parts of the study, writing diaries, and participating in the FGDs and interviews. In the FGDs the themes from the diaries were elaborated, in the interviews the themes were explored in depth. This was also a way to establish prolonged involvement, as the concepts were further developed for every step in the study.

ETHICAL CONSIDERATIONS

Studies I and II were approved by the Research Ethics Committee of Umeå University, studies III and IV by the Research Ethics committee of Karolinska Institutet North. The women were informed about the aim and content of the studies in an introductory letter and asked to participate. Their informed consent was sought and obtained. They were informed about the research both in writing and orally, to enable them to decide whether or not to participate in the different studies. Confidentiality was assured. In all informed consent documents the research staff responsible were presented with names and telephone numbers, to enable the informants to ask questions about the project at any time. It was emphasised that withdrawal at any time, or refusal to participate in the studies, would have no effect on ongoing or future treatment.

FINDINGS/RESULTS

The results of the quantitative studies (I and IV) show different aspects of how women with FM or CWMP can improve in body awareness and movement behaviour after a rehabilitation programme.

The results of the qualitative studies (II and III) suggests that the rehabilitation could be of importance for a process which empowered the women with FM or CWMP to take control over their situation and recovery. Table 6 reviews the results of the four separate studies.

Table 6. Overview of the results of the studies

Study	I Quantitative	II Qualitative	III Qualitative	IV Quantitative
Research question	Effects of a 12-week multi-professional rehabilitation programme?	Experience and gains from a rehabilitation programme?	What strategies do women working despite FM use to control pain, fatigue and other symptoms?	Differences in muscle activity, after a rehabilitation programme compared to before; changes in subjective experience?
Main Results	Treatment group improvements in quality of movement (BAS-H) and perceived vegetative disturbances (BAS interview). Improvements partly sustained after 1 year. Waiting list control group deteriorated.	The women described becoming part of the process “from shame to respect”. They began, and continued, to listen to their bodies, setting limits and improved in self-image. Work situations and limits imposed by illness were negative factors.	The analyses resulted in a “constant struggle” model showing how the women managed. They used a positive spirit to manage active strategies. They stressed the importance of having grieved the loss of the way they used to live. Support from others, specially families, facilitated the struggle.	Muscle activity varied in both groups. Patients decreased muscle activity more than controls in trapezius, non-dominant side, during computer writing and ironing. They tended to decrease activity in infraspinatus during writing and pouring water. Assessed perceived exertion coincided with decrease in muscle activity.

PAPER I. EFFECTS OF A REHABILITATION PROGRAMME

The objective of study I was to evaluate the effects of a 12-week multidisciplinary rehabilitation programme for women with FM or chronic, widespread pain. A treatment group was compared with a waiting-list control group.

BAS-H

Temporal changes

P=0.01 was used as the limit for statistical significance, p=0,05 as limit for tendency. Analysed with Friedman's test for dependent samples (overall), when comparing pre-test values with values at the three-month follow-up (assessments I-II-III) and the one-year follow-up (assessments I-II-III-IV), the treatment group revealed trends towards positive changes in one sub-index of the BAS-H "Flow" index. An improvement was also shown in the single reported interview item "Vegetative disturbances" at the one-year follow-up. However, in the control group negative changes were shown in all three sub-indices of the BAS-H at the three-month follow-up: the grounding/centre-line index, the centring/ breathing index and the flow index.

There were no major changes in the other measurements.

As an illustration of the changes in the BAS-H sub-indices, an ROC curve (fig 5) illustrates the systematic change in marginal distribution between two occasions by plotting two sets of cumulative relative frequencies for the marginal distributions against each other in the "Flow" index of the BAS-H. A systematic change towards lower values in the BAS-H scoring (= improvement), will result in an ROC curve that deviates above the diagonal of unchanged distributions. The greater the deviation, the stronger the systematic change between the two occasions. In the figure the ROC curve illustrating the temporal change within the treatment group between assessments I and III shows a deviation above the diagonal. The ROC curve illustrating the temporal change between assessments I and IV deviates more, illustrating that the values of the BAS-H scoring 'Flow' index were further improved by the one-year follow-up. The change in the control group indicates a more negative change than the positive change in the treatment group. This corresponds with the systematic change over time in the groups shown with the relative position (RP) and the results from Friedman's test.

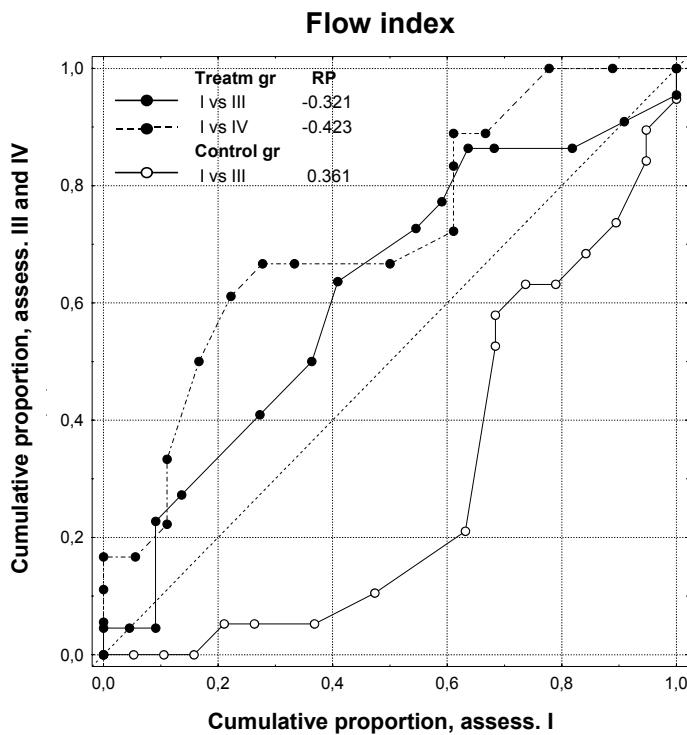


Figure 5. ROC curves for systematic change in Flow index within groups, comparing the cumulative proportion of assessments I and III (X-axis) and that of assessment III in both groups, with assessment IV in the treatment group (Y-axis). RP are shown for each comparison.

PAPER II. EXPERIENCES AND GAINS FROM A REHABILITATION PROGRAMME

The objective of this qualitative study was to explore and analyse how women with FM or CWMP experienced a rehabilitation programme, and what knowledge and strategies they had gained.

The analyses resulted in a model of a process of change, from shame to respect, in which the participants became involved when they started the rehabilitation (fig 6). The process was still going on one year after ending the rehabilitation programme.

The main category '*from shame to respect*' represented the change in the women's emotions and attitudes towards themselves, their illness and their surrounding world. Before entering the programme, the women felt shame because of their illness. They doubted their own experience of pain and other symptoms and they regarded themselves as lazy when they could not manage work as they used to. In encounters with health care, they experienced mistrust and felt that their problems were neglected. When they started rehabilitation, they were met respectfully by the staff and became members of a group, and the shame started to develop towards respect. Self-image improved as did security in relation to others. The positive part of the process was described by three categories; '*developing body awareness/knowledge*', '*setting limits*' and '*changing self-image*'.

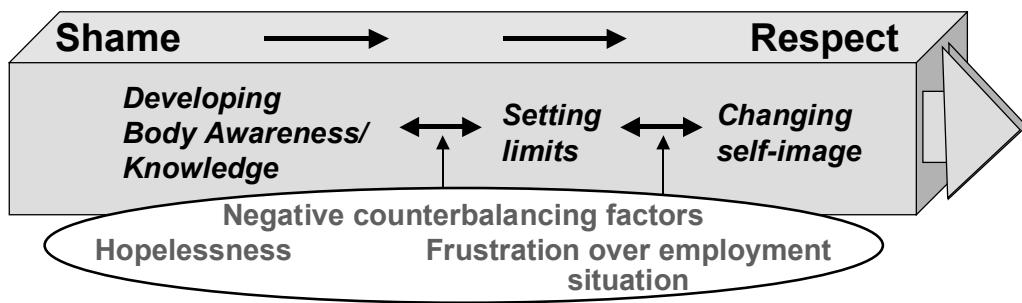


Figure 6. The model describes the process in which the informants became involved from the onset of the programme. On the top is the main category ‘from shame to respect’. Under the main category, categories influencing the process positively are shown. The oval below shows the influence of negative factors.

In the first category, practical and theoretical knowledge about the body and pain mechanisms, together with the beginnings of body awareness, became a starting point for a new approach to oneself, life and the sickness. The women started to learn how to handle their pain and other symptoms instead of denying them, as previously.

The category ‘*setting limits*’ described how body knowledge enabled them to say ‘no’. Adjusting self-demands was described as one of the most important elements in taking care of oneself and gaining control of the symptoms. Awareness of what the body could manage and the importance of respecting one’s own limits so as to avoid deterioration was important for being able to set such limits. When the women started to respect themselves, they could act with greater self-confidence, so their surroundings started to respect them.

The third category, “*changing self-image*”, describes how the women’s self-image improved as they started to become their own experts. When they started to reflect and use carefully developed strategies to handle the pain and other symptoms, they took charge of their own situation. One category ‘*negative counter-balancing factors*’ represented the problems the women had to manage and to overcome. Negative factors still influenced the process and the women’s lives. They knew they would have to continue a struggle against a never-ending illness; that they would never be able to recapture the way they used to live before the pain. Employment was a problem for almost all of them. Those who could continue to work experienced their jobs as stressful and demanding; the sick-listed were bored by not working; and the unemployed felt isolated. No alternative seemed positive or satisfying.

Thus the rehabilitation programme started an extensive process where the women moved from shame to respect.

PAPER III. STRATEGIES USED BY WOMEN WORKING DESPITE FM

The objective of this qualitative study was to explore and obtain increased knowledge about what strategies women who manage to continue to work despite FM use to control pain and other symptoms.

A model with three categories emerged from the analyses (fig 7). The core category, *a constant struggle*, contained eight sub-categories. The *constant struggle* described the women’s never-ending struggle against the symptoms, to change in every aspect of their activities, and against prejudices in their social surroundings.

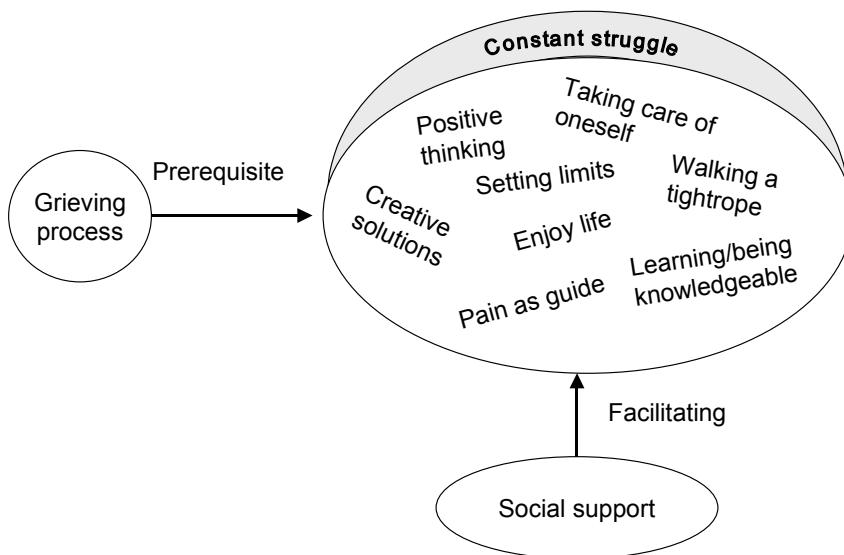


Figure 7. The constant struggle model shows the core category with its eight subcategories and the categories *grieving process* and *social support* which influence the core category.

Two categories which affected this core category were defined in the model. The *grieving process* was a prerequisite for managing the struggle; *social support* contained what facilitated the struggle.

The constant struggle was managed by the eight sub-categories: *enjoying life*, *taking care of oneself*, *positive thinking*, *setting limits*, *using pain as a guide*, *creative solutions*, *learning/being knowledgeable*, and *walking a tightrope*. By adopting the mental attitude *enjoying life* the women consciously turned everyday tasks into pleasure. By *taking care of oneself*, they strove towards bodily balance, careful not to overuse their limited bodily resources. To deliberately use *positive thinking*, the women learned to think that they were content with their lives, except for the FM; and that they managed well. *Setting limits* was difficult but important. It was a matter of adapting life and oneself to one's own limitations. The women learned their limits by trial and error. *Using pain as a guide* was a strategy used by some who had developed an awareness of sensory information from their bodies, learning to feel the subtle warnings from a slight increase in pain or stiffness during activity, when they risked a worsening of symptoms. By immediately interrupting the activity for a short rest, they were able to prevent the pain or the fatigue from increasing. To be sensitive enough, they had to refrain from pain medication, since this rendered them insensitive. Through *learning/being knowledgeable* the women kept up-to-date with all information about FM. This helped them to find new strategies and to feel secure in that their pain was not dangerous. The women became skilful at developing *creative solutions* for tasks which they found difficult to manage. At work as well as at home they had to find ways to manage physically-demanding or stressful work tasks. They solved the problems with ingenuity and careful planning.

The women described their work situation as *walking a tightrope*. They had to balance carefully, or they risked falling. Work was considered important and joyful, but they were anxious about how they would manage in the future: would they be able to continue? Everything in life had to be planned in regard to work. To be at work at eight could mean waking up at five to get enough time to make the body function. Those who had flexible working hours regarded them as necessary for managing work.

The category *grieving process* describes how the women had worked through and accepted the loss of their former selves and their former bodies. Grieving led to a turning point where they could develop new ways of managing life: this process was necessary for developing the strategies described. *Social support*, mainly from the family, was important. Few felt support from colleagues; a supportive superior was more common.

PAPER IV. CHANGES IN MUSCLE ACTIVITY AFTER A REHABILITATION PROGRAMME

The objective of study IV was to investigate whether patients with fibromyalgia had learned after a rehabilitation programme to perform tasks with less muscle activity than before the programme and compared to a healthy control group. And if so – to find out whether these changes were measurable with S-EMG. A second objective was to investigate whether pain intensity and perceived exertion were affected in women patients with fibromyalgia after a rehabilitation programme as compared to before the programme.

Between-group changes

$P=0.05$ was used as the limit for statistical significance, $p=0.1$ as the limit for a tendency. The patients with FM decreased their muscle activity level significantly in trapezius pars descendens, non-dominant side, compared to the healthy controls in %subrefEMG during computer writing and ironing, on the second measurement occasion compared to the first. On the second measurement occasion muscle activity level in μV during computer writing had also decreased significantly in trapezius pars descendens, dominant side, compared to that of healthy controls and compared to the first occasion. The healthy controls showed significantly lower muscle activity level in extensor digitorum than the patients, measured in %subrefEMG and μV , while ironing on the second occasion compared to the first. Tendencies towards between-group changes, where the patients tended to reduce their muscle activity more on the second occasion compared to the healthy controls, were seen in trapezius dominant side in %subrefEMG during ironing and vacuuming under chairs, and in μV while vacuuming; in infraspinatus in %subrefEMG during computer writing and pouring, and in extensor digitorum in μV while pouring water into glasses.

Within-group changes

The patients with FM had decreased their muscle activity level significantly by the second measurement occasion compared to the first in trapezius pars descendens non-dominant side in %subrefEMG during ironing; in trapezius pars descendens dominant side in %subrefEMG during ironing, in infraspinatus in %subrefEMG during ironing and in extensor digitorum when pouring water in glasses in μV .

The healthy controls decreased their muscle activity level significantly on the second occasion compared to the first in infraspinatus in μV during ironing, and in extensor digitorum in %subrefEMG while vacuuming under chairs.

Assessment of pain intensity and perceived exertion after performing tasks

All the healthy subjects rated zero pain intensity after the tasks, as did most subjects in perceived exertion. The patients rated higher pain intensity and perceived exertion, e.g. median 36 in pain intensity and median 36 in perceived exertion, after computer writing on

the first test occasion. Borg CR100 scale 36 corresponds to a value between moderate and severe/heavy

After the rehabilitation programme the patients had decreased their perceived exertion after writing on the computer and after ironing. They tended to decrease their rated pain intensity after writing on the computer. These results indicate that after training a movement pattern with less muscle activity, patients with FM can write on a computer and iron with decreased perception of exertion.

DISCUSSION

FM/CWMP are multifactorial, complex disorders that can be studied from many different perspectives. The present work focused on the effects of multiprofessional rehabilitation and what strategies women with FM/CWMP used to manage work and everyday life. Two different research approaches were applied: quantitative methods were used to compare groups and measure changes over time, while qualitative methods were used to explore experience and strategies.

The rehabilitation programmes were planned to take into account the women's individual needs.

The results show that women with FM and CWMP gain from multiprofessional rehabilitation in several ways. Improvement in 'body awareness/knowledge' and working through a process of grieving/accepting that life has changed were important for the participants, in order to find new, useful strategies for managing an active life. These results accord with those of previous research (58, 125). The improvement in 'body awareness/knowledge' started during the programme, while the start of grieving/accepting a change in life differed. Some women had already begun the process when their rehabilitation started, others started during the programme and still others started later. As found in study III, the women regarded the rehabilitation programme as important for the process.

The three perspectives: pain physiology, rehabilitation medicine and gender theory proved useful in the interpretation of the results in the four parts of the present work.

BODY AWARENESS/KNOWLEDGE

Body awareness/knowledge was an important point of entrance for the women with FM and CWMP. Starting the rehabilitation process by acknowledging the women's bodies and helping them understand that they had knowledge within themselves if they just 'listened' to (became aware of) and acknowledged it, initiated a process of empowerment within them. Self-respect, awareness of one's own needs and the ability to "listen to one's own body" seem important for patients with FM/CWMP to live as active a life as possible despite persistent pain and fatigue.

Engelsrud (76) discusses how the body becomes a point of determination. On one hand it is easily associated with sickness; on the other it is also a centre of experience. We can either act from the perspective that the body is something that we just *have* (body as object – the dualistic tradition), or from the perspective that we both *are* a body (state of experience – the dialectic tradition) and *have* a body. Physiotherapists, like other professionals who work with other people's bodies, are supposed to promote strengthening of the status of the body. This may either occur as a diagnosis or by establishing the body as a 'personal home', a centre for experience and acknowledgement recognition (76).

Modern, western culture tends to idealize the human body (67, page 86). Body ideals do not only concern appearance, but also the notion of the body being strong, agile and controllable. This idealization contributes to the objectification of the body together with the dualistic split of body and mind. When the body becomes objectified it is regarded primarily as a ‘physical object to be viewed, used and manipulated’, the woman ignores her inner subjective experience of her body (67). In study II the women described how they before rehabilitation viewed their bodies as something that could be ignored or compelled to act. Ideas such as ‘you just have to do some exercise’ or ‘it is all a matter of positive thinking’ were common both among themselves and among health care staff. ‘Because our minds are much bigger than our egos, and because we are not consciously aware of what takes place in our minds, the mind-body relationship is far more mysterious and complex than the mind-over-body version of the myth of control implies’ (67, page 103).

The view of the human body as something that has to be either controlled or manipulated prevents us from experiencing and understanding ourselves as both *being* and *having* our bodies. Body awareness therapies, such as Basic BAT and Feldenkrais, try to promote the experience of being our bodies, that we in our bodies experience feelings and sensations and live our lives. Our bodies guide us in understanding our own needs and limits, where we also can comprehend suffering such as pain.

In terms of the physiology of chronic pain, improved body awareness can be hypothesised as being of value in FM/CWMP. By avoiding longstanding, unnecessary muscle tension and positions where the joints are in extreme positions, fewer factors may maintain the central sensitisation. Improved body awareness may also help the sufferer to sense signs of increasing stress and overload.

ENCOUNTERS IN HEALTH CARE

In several studies (69, 101 [study II], 125, 126), patients with FM and other chronic pain conditions describe how they are met, by health care staff, with disbelief and blame, are accused of exaggerating symptoms and being lazy. In study II, the women described how they sometimes started to doubt their own experience and sanity: how could their pain be real when tests or X rays showed nothing? When they experienced doubt from physicians and others in health care, no wonder that also their employers, colleagues and families questioned the degree of their impairments. Diffuse pain conditions, which are more common in women, have been found at the lowest level of the cultural medical hierarchy of diseases (70).

Medicine highly values objective symptoms, which are measurable and visible (69); subjective symptoms and descriptions are often viewed as less important and can always be suspected of being false or exaggerated (59). For many patients the diagnosis FM means stigmatisation, that their moral integrity is being questioned and their symptoms assumed to originate from psychological causes (72, 101 [study II], 125). The experience of stigmatisation is a powerful obstacle in the relations between patients and health care staff. As long as personal integrity is in question, the person will fight against the stigmatisation, and not until the health care provider recognizes the suffering of the woman patient does it become possible for the latter to concentrate on dealing with how to live with continuous pain, instead of struggling to maintain her dignity (61).

RECOGNITION

In an interview study, Werner et.al. (65) explored the nature of the benefits from a rehabilitation programme for women with chronic musculoskeletal pain. The women

specified the importance of feeling respected and how they gained strength, confidence and awareness from this. They reported that being aware of and setting limits to their own daily capacity was closely related to permitting themselves to adapt to their own needs and desires. These results tally with our results in study II, where women interviewed one year after participating in a rehabilitation programme described how they got involved in a process where their feelings towards themselves and their illness developed from shame to respect. The recognition they got from being members of a group and participating in rehabilitation gave them both self-respect and respect from others. When they started to recognise their bodily needs, they also grew aware of, and permitted themselves to satisfy, their own needs. In the study by Werner (65), the interviewed women achieved “recovery competence”; they found a way to live a satisfying, hopeful and contributing life despite the limitations caused by chronic pain. Being accepted and met with respect in a treatment programme helped the women to recognize both their limitations and their capacity. They were empowered.

Mengshoel (125) interviewed women who had recovered from FM. They regarded trust and support as crucial for the recovery process. They had learned to listen to their bodies and take into account the accumulated strains of their whole life situation, not only the strain of a single activity. The women felt “their bodies told them” when they had stored up too much stress. They recognised the stress through increased pain and muscle tension. These signals made them stop and reflect on their current situation. When they followed such strategies, they knew they would improve in a few days. They had learned to analyse their situation and they knew what was good and bad for them. All the women had given priority to their own needs; most of them had achieved higher education, which gave them new professional possibilities. In this process their self-esteem and self-respect increased. It was important for all who recovered that they did not identify themselves with a sickness role: instead they struggled to maintain their normal social roles and life. According to Mengshoel’s study, it is important that rehabilitation programmes do not have the symptoms control the patient instead of the opposite. Patient education programmes and cognitive behavioural programmes teach people how to cope with symptoms by adjusting their lives to the symptoms. Adjustment to symptoms may over-emphasise what the patient cannot do and result in a sickness role, instead of emphasising resources, possibilities and what the patient wants to do. In study III analysing the strategies used by women working despite FM, many of the strategies required reflection and skill. The women had learned to respect their own limits and allowed themselves to enjoy life. They emphasised that, after grieving for the parts of life they could no longer live, they could find and use these strategies, identifying new possibilities and goals in a new way to live, new ways to do what they wanted. They did not adjust to the pain in terms of giving up, but the new ways were achieved by respecting what they felt in their bodies.

REHABILITATION AS EMPOWERMENT

One way of defining medical rehabilitation is to look upon it as empowerment, a concept used when patients increase control over their lives. They become able to perceive alternatives, make choices and fulfil them (6).

The possibility to continue working is connected with new strategies and improved self-esteem. These can be gained during rehabilitation.

Our results indicate that the present rehabilitees became involved in an empowerment process.

When the women in study I improved in movement quality, they began to take own control through awareness and knowledge of bodily reactions. What they did and how they did it

affected their problems. In study II, the same women demonstrated that the rehabilitation programme had had a greater impact. They had started to become their own specialists, not only resuming command of their bodies but also regaining self-respect and respect from their social surroundings. In study III, the participants had experienced their rehabilitation many years previously, and therefore the impact the rehabilitation had on their current ability to manage so well could not be determined. Yet many of them referred to special moments during the rehabilitation programme: when they had met respect during encounters with rehabilitation staff, or when they had gained valuable insights about how to manage their problems.

The women included in study IV demonstrated how they had learned to perform practical tasks with less muscle activity in shoulder muscles and less exertion.

When rehabilitation aims at restoring women's work capacity, their household work is an important aspect. In women's reality, separation into unpaid, household, work and occupational life (127) is often impossible. In study III the informants described household activities as "work": they had to prepare themselves and plan for paid work and housework in the same way: in their discussions they made no difference between the two.

Studies of gender differences in rehabilitation outcomes highlight different conditions and outcomes for men and women. Thus Ahlgren (128) found that the most important factor for successful rehabilitation in terms of returning to work was to be a man. Possible explanations of this (57) are that men more often received specific diagnoses and developed good relations with their physician from whom they could require further examinations if the pain persisted. The women hoped for help but experienced distrust on the part of the physicians (57). When rehabilitation reached the point of return to work, men often managed to get approval from the social insurance officers for exceptional measures while women felt that the decision was made over their heads, or that they were abandoned. The men regarded themselves as striving for full-time paid work. The women's goals included both work and family; they rejected training programmes because they had the responsibility for the care of their children. This could cause social insurance officers to regard male clients as more motivated for rehabilitation than female.

Also, Hamberg found that rehabilitation programmes for women patients with musculoskeletal pain do not take account of the terms of the 'marriage contract' (60), which have implications for women's return to work. Gender structure within marriage gives the woman the main responsibility for children and domestic work. Women have limited possibilities of changing this in a situation where first rehabilitation and then work would take effort and time.

Jensen (49) found in a three-year follow-up of a multiprofessional cognitive-behavioural rehabilitation programme for patients with low-back pain that the women benefited more than the men. The men seemed less likely to believe in the positive effects of such a programme. This programme was more extensive than the two discussed earlier (57, 60), with both individually-adjusted exercises and cognitive behavioural therapy as pain management. Pain management including i.e. activity planning, goal setting and activity pacing, might more often appeal to, and be more valuable to, women.

To succeed, rehabilitation needs to recognise the different conditions for men and women as individuals; in particular women's responsibility for child care, and to deal with the problem in a respectful way. Rehabilitation where individuals can choose measures based on their own experienced needs and possibilities might offer a way of meeting future demands.

PAIN AS A GUIDE

In study III a highly developed level of body awareness was found among the informants. By being attentive to their bodies, they could sense the moment during an activity when they were in danger of deterioration, and could avoid this if they stopped the activity at once. Sensing this is very difficult for people with FM. They usually do not feel symptoms of increased pain or stiffness until later the same day or even the next day. In physical exercise, it is hard for them to sense when their bodily limits have been reached. The women in study III who could sense deterioration in time agreed that pain medication prevented them from being sensitive enough. However, their constant attention to bodily sensations and their attempts to respect these differs from 'fear-avoidance'. One woman described how, to refine her 'sense of pain', she had explored the limits of pain, knowing that doing so was not dangerous. Others described how they used pain medication when they knew that they had to exert themselves with no possibility of rest; but on these occasions they also knew they would get increased pain later.

These descriptions illustrate the importance and possible gains of work with body awareness. The present informants' successful strategy contradicts current discussion of the advisability of recognizing pain. In behavioural medicine (129) it is sometimes claimed that pain increases by attention. However, the kind of attention described by the informants in the present studies is, I submit, constructive and helps them to gain own control over the pain. Steilhaug and Ahlsen describe a similar process (63, page 208). The ability to work with our bodies during mental awareness can lead to increased self-knowledge and recovery competence. Their study evaluated combined training in body awareness with group discussions characterised by acceptance, a sense of belonging and cooperation (58). The women participants described a process of becoming their own experts after participating in the groups.

EVALUATION OF MOVEMENT BEHAVIOUR: ITS CLINICAL SIGNIFICANCE

Change in movement behaviour or movement quality after a rehabilitation programme was evaluated in two ways, BAS-H and S-EMG. In study I where the BAS-H was used the physiotherapist assessed the patient's ability, pattern of motion, breathing pattern and general behaviour during everyday movements with a structured movement test. In study IV muscle activity during four different tasks was measured with S-EMG. Both studies indicated that patients with FM (and WCMP in study I) could learn different movement behaviour after Basic BAT and EMG-biofeedback training. This can be illustrated with two diagrams from study IV, showing muscle activity in one patient before and after the rehabilitation programme. The diagrams show how the muscle activity illustrated with %subrefEMG decreased during ironing after the rehabilitation programme and how pain intensity and perceived exertion coincided. In patients who according to EMG did not change their movement behaviour, the pain intensity and perceived exertion did not decrease.

Studies evaluating effects of training programmes are rare. Vollenbroeck-Hutten et.al. investigated whether changes in pain induced by myofeedback training are related to changes in muscle activation patterns. Subjects with work-related myalgia trained with a portable myofeedback system (130) during four weeks. The training sought a normalisation of muscle activity patterns, i.e. sufficient muscle rest during the tasks, which was supposed to contribute to pain reduction. A standardized typing task and a stress-related computer mouse task were evaluated with S-EMG. The results suggest that pain observed at long-term follow up after myofeedback training might decrease as a result of an increased ability to relax, but not as a result of decreased muscle activity. The present study IV did not include any long-term

follow-up, the changes seen in subjective ratings being mainly in perceived exertion. In study I, at the one-year follow-up, improvements in movement behaviour were partly sustained, but no changes were seen in pain intensity.

With the physiology of chronic pain in mind, these results can be understood hypothetically. When mechanisms of chronic pain are established in a sensitised nervous system, the pain is difficult to alleviate by e.g. relaxation only. If some other impairment factor, such as high muscle activity, decreased for some time, pain intensity might decrease.

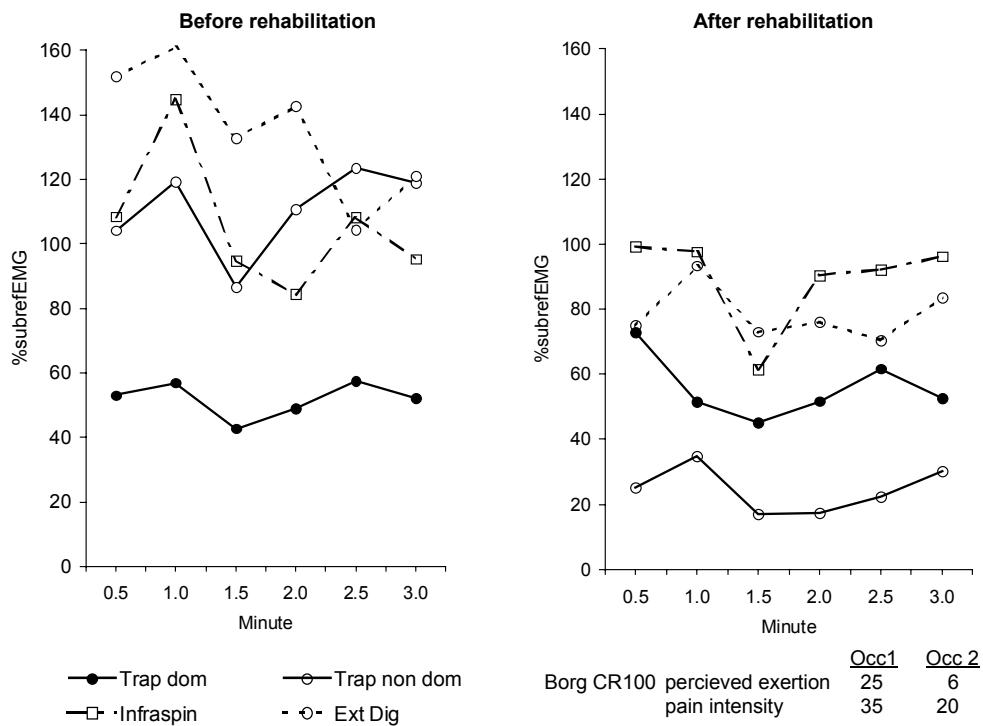


Figure 8. Muscle activity in %subrefEMG (vertical axis) before and after rehabilitation, during 3 minutes (horizontal axis) of ironing in trapezius pars descendens bilaterally, infraspinatus and extensor digitorum of dominant side. Perceived exertion and pain intensity assessed with the Borg CR100 scale are shown below.

METHODOLOGICAL CONSIDERATIONS

Many different methods were used in this thesis. More in-depth description and discussion is given in the four papers.

Participants

All the women in the studies presented in this thesis were examined and diagnosed by a physician specialising either in rheumatology or rehabilitation medicine at a specialist clinic or a university clinic. The diagnosis FM was given according to the ACR criteria (2). The women with the symptom diagnosis chronic, widespread musculoskeletal pain (CWMP) (studies I and II) did not fulfil all the criteria for FM, but had generalised pain. The reason for including women with either diagnosis in studies I and II was pragmatic. The rehabilitation programme evaluated was financed by the local social insurance offices, the officers there deciding whom to send for rehabilitation. If only women with FM had been included, the study sample would have been very small!

Since all the women had been referred to specialist clinics, it can be assumed that their pain and other symptoms were more disabling than what is seen in an FM or chronic-widespread-pain population at primary care level (131).

In studies III and IV only women with FM participated. The rehabilitation programmes in these studies were exclusive for patients with FM. Recruitment of participants for studies I and IV was consecutive since randomisation was impracticable. This is a common problem in clinical studies, especially when the number of patients at rehabilitation centres is limited.

In studies II and III, all those who fulfilled the inclusion criteria and agreed to participate were included.

The participants in studies I and II lived in a sparsely-populated rural area in northern Sweden while those in studies III and IV lived in Stockholm, the capital. It is possible that their different living conditions e.g. possibility to find new jobs, affected the results. The results of studies II and III point in the same direction, although the women probably lived under different circumstances and had partly differing diagnoses. This can be viewed as strengthening the transferability (generalisability) of the results.

S-EMG methods

The methods of electrode placement and sub-maximal reference contractions in study IV were carefully developed. In the protocol for each measurement occasion, the distances between anatomical landmarks were noted to ensure that the second placement was as close to the first as possible. The mid-point between the two electrodes for each muscle was marked with a pen and the electrodes were placed thereafter.

For the sub-maximal reference contractions for infraspinatus, the angle of shoulder abduction was measured with a goniometer. During all reference contractions, the first author stood by to facilitate the desired performance.

When designing the sub-maximal reference contractions and the tasks, we were aware of the problem of standardisation. Since we did not know whether it was possible to measure a change in movement behaviour in this way we were prepared that our method would have to be further developed.

The concepts of the International Classification of Functioning, Disability and Health (ICF)

The ICF structure (132, 133) has gained much recognition. Core sets of ICF categories have been presented for chronic conditions, e.g. chronic widespread pain (134). The present work has, in terms of ICF, a main focus on muscle functions, movement functions, and pain sensations as body functions and – at the level of activities/participation – mobility and major life events. However, several other functional consequences of disease are presented in the thesis and the studies on which it is based, but categorisation according to ICF has not been applied, partly because the new ICF model was not finally published when the present studies began.

Combining quantitative and qualitative methods

Combining qualitative and quantitative methods is becoming increasingly common in medicine, although qualitative research is still rare. Qualitative research aims at understanding more than at explaining, and adds new perspectives on the phenomenon studied.

Rehabilitation is an area where important knowledge can be added from qualitative studies (105). When supporting patients in regaining their abilities, their perceptions, thoughts and experience are of crucial importance for success. Quantitative and qualitative methods can supplement each other, describing the phenomenon from different perspectives in a kind of triangulation, and thus strengthen the results (104, 135).

SUMMARY OF RESULTS AND CONCLUSIONS

By participating in a multiprofessional rehabilitation programme with emphasis on physiotherapy, the women with FM or chronic widespread pain became engaged in a process where their feelings and attitudes towards themselves, the pain and their social surroundings changed from shame to respect. Greater self-confidence resulted in more respect and increased understanding from family, friends and health care staff.

The starting point of the positive process was increased body awareness/knowledge. The women's work with their bodies in the group initiated several positive changes. They began to acknowledge their needs and boundaries. This action helped the process of 'changing self-image' towards recognition, and upward valuation of the self continued.

The multiprofessional rehabilitation programme with emphasis on physiotherapy improved quality of movement and reduced experience of vegetative disturbances in women with FM or CWMP. The improvements were partly sustained at the one-year follow-up.

The programme had little effect on pain intensity, pain dispersal, consequences of pain or quality of life as measured with VAS, pain drawings, MPI and QLS.

The women who managed to continue working despite FM fought a constant everyday struggle against the consequences of FM and the prejudices in their surroundings. They employed a variety of strategies, all consciously active, with a positive spirit and carefully applied.

The women with FM could learn to sense deterioration during activity as a result of highly-developed body awareness. If at the very moment when they sensed the slightly increased pain or stiffness they were able to stop the activity and have a short rest, they could prevent deterioration.

To manage the struggle and develop purposeful strategies, the women with FM reported that it was important to grieve for the loss of their former lives if they were to manage to start a new one.

Social support, especially from family, facilitated the struggle. Support from employers was important for managing the work situation.

The results from studies II (rural) and III (urban) partly support each other despite the informants' differing living conditions. This supports the transferability of the results.

Women with FM were able to perform different tasks with less shoulder-muscle activity after a rehabilitation programme than before.

A decrease in assessed perception of exertion after two tasks indicated that this decrease might follow the decrease in muscle activity.

CLINICAL IMPLICATIONS OF REHABILITATION FOR WOMEN WITH FM/CWMP

The results indicate that rehabilitation measures used in the rehabilitation programmes evaluated can benefit women with FM/CWMP. One important feature was the encounter with the rehabilitation staffs, who were knowledgeable, experienced and had a respectful and holistic attitude. The therapeutic value of such encounters can never be sufficiently emphasised.

Rehabilitation programmes entailing body awareness therapy and work training with EMG-biofeedback can help women to change their movement behaviour and find more functional positions and movement patterns with less muscle activity. Body awareness therapy and work training with EMG-biofeedback are important parts of rehabilitation programmes for these women.

The strategies described by the women in study III can be viewed as a ‘smorgasbord’ of useful strategies that can be discussed during a rehabilitation programme. Not all the strategies suit all the patients; but it might be helpful to learn that others with FM are helped by using them.

The importance of the right timing of rehabilitation was emphasised in study III, where the women stressed that in order to develop and use purposeful strategies, they had to have worked through a process of grieving the loss of ‘the parts of life they could no longer live’. When a rehabilitation programme aims at supporting the achievement of new strategies and work resumption, it seems important that this grieving-process should at least have begun.

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