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Women with fibromyalgia

Employment and daily life

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To Stefan, Fredrik, Gustav and Jon

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Abstract

Introduction: The major symptoms of fibromyalgia have been shown to severely impact everyday activities. As a consequence, many women have problems remaining in a work role. Not being able to fulfil valued roles influences quality of life. Moreover, consequences in terms of high costs in compensation for reduced work ability are also of importance for society. Today, the number of young women diagnosed with fibromyalgia is increasing.

Objectives: The general aim of this thesis was to increase and deepen knowledge of the life situation of women with fibromyalgia; to examine how to manage a work role when in constant pain, and especially the situation for newly-diagnosed women.

Subjects and Methods: 278 women with longstanding pain were included. The thesis includes five different studies, two of them with a focus on the work situation, two with focus on young, newly-diagnosed women's life situation, and one investigating time-use and activity patterns in working and non-working women with fibromyalgia. Methods used are a postal questionnaire, instruments commonly used in fibromyalgia, a diary, and interviews.

Results: Despite limitations in physical capacity, 48% of the women are working, full-time or part-time. However, most job loss is associated with the fibromyalgia symptoms, and the women report that the symptoms influence their daily activities during most of their waking time. There is a rapid increase in sickness absence in the newly-diagnosed women, and the young women in particular do not return to the labour market during the first year after receiving their diagnosis. The non-working women have a more demanding family situation, and are also less satisfied with their present situation than working women.

Conclusion: When individual adjustments of the work situation are made and the women participate to a level that matches their ability, they are able to continue in a work role. In evaluating the women's work capacity, the total life situation of the women should be considered.

Keywords: work role, newly-diagnosed, time-use, activity pattern, family work.

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List of papers

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Henriksson C, Liedberg G. Factors of Importance for Work Disability in Women with Fibromyalgia. *J Rheumatol* 2000;27:1271-6.
- II. Liedberg GM, Henriksson CM. Factors of Importance for Work Disability in Women with Fibromyalgia: An Interview Study. *Arthritis Care Res* 2002;47:266-74
- III. Burckhardt CS, Liedberg GM, Henriksson CM, Kendall SA. The Impact of Fibromyalgia on Employment Status of Newly-Diagnosed Young Women. (submitted)
- IV. Liedberg GM, Burckhardt CS, Henriksson CM. Young Women with Fibromyalgia – Perceived Difficulties the First Year after Diagnosis. (submitted)
- V. Liedberg GM, Hesselstrand ME, Henriksson CM. Time Use and Activity Patterns in Women with Long-term Pain. *Scand J Occup Ther* 2004;11:1-10.

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Abbreviations

IASP International Association for the Study of Pain

ACR American College of Rheumatology

FM Fibromyalgia

FMS Fibromyalgia Syndrome

RA Rheumatoid Arthritis

CNS Central Nervous System

NMDA non metyl-d-aspartat

WDR Wide Dynamic Range

DNIC Diffuse Noxious Inhibitory Controls

CFS Chronic Fatigue Syndrome

WSP Widespread chronic pain

ISCO International Classification of Occupation

FIQ Fibromyalgia Impact Questionnaire

SF-36 The Shortform Health survey

BDI Beck Depression Inventory

BDI-A Beck Depression Inventory-Adapted version

BAI Beck Anxiety Inventory

AIMS II Arthritis Impact Measurement Scales II

CA Content analysis

NUD*IST Non-numeric Unstructured Data Index Searching and Theorising

ASES Arthritis Self-Efficacy Scale

HPA Hypothalamic – Pituary – Adrenal axis

SPSS Statistical Package for Social Science

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Introduction

The daily lives of women with fibromyalgia are the focus of the present thesis. In the fibromyalgia population, 90% are women (1), and deeper knowledge is needed of their life situation. Research on fibromyalgia is extensive, but few studies consider the issue of employment. More knowledge about which factors impact employment would benefit society and the individual with longstanding pain. Only two articles studying newly diagnosed people with fibromyalgia have been published: how they experience daily hassles in their life (2); and the clinical outcome in women being diagnosed with fibromyalgia (3). More data about the situation of newly diagnosed young women are needed to support the development of early interventions that will prevent long-term negative outcomes and increase the health and quality of life of young women with fibromyalgia. In this thesis, work role, employment and working outside the home are considered synonymous. The present thesis is based on three studies, including 5 papers, performed during 1997 – 2003.

Women and employment

In Sweden 74% of women aged 16-64 were occupied in the labour market in 2001 (4). Although most women participate in the labour market, gender segregation has remained strong in occupational areas such as health care, where female workers dominate. Segregation is also strong within the same occupations, resulting in different tasks being performed by women and men (5). The majority of women, 33%, were employed in health care and social work, and 15% were employed in the wholesale and retail trade, which includes transport, storage and communications. Further, 12% of the women were employed in financial intermediation, such as real estate, renting and business activities. Women are represented in 18 of the 25 occupations where the risk of musculoskeletal disorders is the most frequent. These include food processing, manufacturing and construction, packing and storage work, electrical and electronic work, and cleaning. The highest risks and most frequently reported cases of musculoskeletal accidents are from trained home help, and health care workers (6). Women perform more repetitive work than men, with tasks requiring high static load on the neck and shoulders. Thus, risk patterns of musculoskeletal disorders differ for men and women because they work with different tasks (5).

The Swedish Labour Force Survey (4) from 2001, showed that 66% of employed women worked 35 hours/week or more. Twenty-four percent of the employed women aged 50 – 64, reported that they would not be able to work until normal retirement age in their present occupation. They indicated the changes that would be required to enable them to work until normal retirement. More than half of the women proposed shorter working hours, and 22% suggested that working hours should be more flexible. Other proposals included changes in the physical and psychosocial working environment. According to 58% of the women, the ability to remain in the work role also depends on a change of pace at work.

A 4-year longitudinal study performed in Sweden by Bildt and Michélsen (7) of men and women aged 18-65 shows that non-occupational factors, such as living alone, poor social relations, and demanding life events, did not reduce the importance of occupational risk factors. Factors such as high perceived work load, shift work, temporary employment, and job strain contribute independently to poor mental health. In general, women have been shown to have lower psychological well-being than men, and employment is regarded as contributing to better mental health. It is likely that occupational and non-occupational factors interact and contribute, and must therefore be considered (7).

Studies performed by Frankenhauser (8) and Lundberg et al (9) show that women's overall life situation influences the risk pattern. Women have the main responsibility for unpaid work in the home, resulting in greater overall exposure to physically demanding activities and psychosocial strain. This influences their ability to recover after work. It has been shown that a large part of the total physical load and psychosocial strain derives from activities outside work, and that this is more common for women than men (8, 9). Job strain in work with high demands and low control is related to ill-health and lower work capacity (10). Women also report higher effects of job strain than men as a result of the combined burden of paid and unpaid work (11). This was studied by Krantz and Östergren (12), who investigated how heavy domestic responsibilities combined with job strain influenced women aged 40-50 regarding common symptoms frequently reported in population-based studies. They found that both factors independently and a synergy of the factors, were associated with common symptoms in the women. Symptoms such as tiredness, muscular tension, head ache, pain in the joints, and low back pain were more highly associated for women exposed to the double burden.

Women and sickness absence

When work capacity is reduced due to ill-health, sickness benefits are a social right in Sweden. In a review article by Alexanderson (13) concerning sickness absence, three levels of theories of sickness absence were found: national, workplace and community, and individual. On the national level, factors such as economic recession, unemployment, gender segregation, structural rationalisations, the sickness insurance system, and general changes in attitudes in society are significant. Theories on workplace and local community have focused, for instance, on the relationship between the work environment and sickness absence, as well as the absence culture at work, i.e the shared understandings of absence legitimacy. Further, access to day care, health care, different types of jobs, and public transportation are regarded as factors that influence sickness absence. Finally, at individual level, personal characteristics are emphasised, including age, gender, life style, family situation, and working hours. The impact of the individual's attitudes towards sickness absence and the motivation for work are regarded as significant. Alexanderson (13) concludes that a medical perspective is missing and, in order to gain more knowledge about specific diagnoses and their related sickness absence, this perspective must be included. Thus, the concept of sickness absence is a complex phenomenon reflecting not only disease, but also aspects such as the social insurance system, individual job satisfaction, and psychosocial work characteristics, as well as attitudes and health care practices (14).

In Sweden, in 2001, women accounted for 58% of the costs of sickness absence (15). Several investigations have shown higher sickness absence among women than men (16-18), especially in gender segregated occupations (17). When pregnant women were excluded the sick leave rate was 25% higher than in men (18). In an 11-year prospective cohort study (14) of people with neck, shoulder, or back diagnoses, sick-leave factors that could predict a disability pension were investigated. Factors known to predict long-term sickness absence were: higher previous sickness absence, female gender, foreign citizenship, manual labour, and lower socioeconomic status. Within 11 years, 27% of the women and 14% of the men were in receipt of a disability pension. The highest risk for permanently sicklisted was shown to be citizenship, sex and the number of sick leave days per spell (14). A three-year prospective study (19) considering work status and disability pension investigated persons with long-term sickness absence, where musculoskeletal health problems constituted the main diagnostic group. Predictors for disability pension were age, part-time employment, and absence in excess of 197 days. After approximately 270 days, the risk of permanent

sicklisting increased rapidly, with a 40% risk of future early retirement due to illness for spells that reached 365 days of absence.

Longstanding musculoskeletal pain conditions are common and contribute to reduced work capacity in a large portion of the working population. This results not only in suffering and a lower experienced quality of life but also in high costs for society. Chronic pain conditions in muscles and joints are the most common reasons for receiving disability pension, although the trend is decreasing (20). These conditions account for the highest indirect costs (fall in production as a consequence of reduced work ability) when compared with other diseases (21). The total cost of rheumatic diseases in Sweden in 2001 was approximately 36 billion Swedish crowns. People with soft-tissue conditions (including fibromyalgia and other fibromyalgia similar conditions) consumed health care for 865 million Swedish crowns and accounted for approximately 13 billion Swedish crowns in indirect costs (22)

Fibromyalgia

Definition of pain and fibromyalgia

The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (23). Pain is thus defined as both a sensory and affective experience.

Fibromyalgia is characterised by persistent, widespread muscle pain with generalised hyperalgesia and allodynia (24). It is the generalised allodynia/hyperalgesia (see definitions Figure 1) that distinguishes fibromyalgia from other longstanding muscular pain conditions.

Tender point: the presence of tenderness on palpation with a pressure of approximately 4 kg (24)

Allodynia: pain due to a stimulus which does not normally provoke pain (23)

Hyperalgesia: an increased response to a stimulus which is normally painful (23)

Nociception: “Events in the peripheral and central nervous system that are associated with the processing of electrical signals elicited by tissue-threatening stimuli” (25, p 356)

Figure 1. Definitions

In 1990 the American College of Rheumatology (ACR) proposed classification criteria for fibromyalgia, based on one symptom, pain, and one finding on examination, namely pain on palpation of specified locations, so-called tender points (24).

- A widespread pain must be present, which means pain in all four quadrants (left and right side, upper and lower half of the body, and axial pain) The pain must also be long-standing i.e be present for more than three months.
- On palpation with moderate pressure, the person should express pain, not only pressure or tenderness. The presence of tender points is tested at 18 specified locations. For diagnosis, there should be tender points on at least 11 sites (24).

Epidemiology

Pain is a common symptom in the general population. An epidemiological study (26) performed in the county of Östergötland, Sweden, shows a prevalence of 61.3% of pain on several occasions during a 3-month period, and that the prevalence was related to age. The age group 50-64 years had the highest prevalence of pain. In two other studies from Sweden and the USA, the prevalence of longstanding muscle pain was 35% and 31%, respectively (27,28). Further, population-based studies, performed in the USA, the UK and Sweden investigating the prevalence of chronic widespread pain without the generalised allodynia present in fibromyalgia, show a frequency of 10-11% (1,27,28). Both chronic widespread pain and regional pain are about 1 ½ times more common in women than in men (28).

The prevalence of fibromyalgia is approximately 2 % in the population (1,29), and the diagnosis is six times more common in women than in men (1). Fibromyalgia can also be diagnosed in children (30-32). Since the condition in most cases is permanent, the prevalence increase with age and is highest in women over 60 (1). Fibromyalgia is often associated with other conditions where there is longstanding muscle or joint pain. Clauw and Paul (33) show that 20% of patients with rheumatoid arthritis (RA) also have fibromyalgia.

The concept of fibromyalgia

In the literature there are three different models for the pathogenesis of fibromyalgia.

1. According to the ACR criteria fibromyalgia is a musculoskeletal pain condition characterised by multifocal pain and generalised allodynia/hyperalgesia. There are grounds to believe that fibromyalgia is the final stage in a process starting with long-lasting local or regional musculoskeletal pain (for references see 34). Stress-related symptoms are considered to be secondary to pain and pain hypersensitivity.

2. Fibromyalgia is a chronic stress syndrome. Pain is one of many possible stressors. Fibromyalgia is one expression of a “multi-symptom syndrome” like a number of other conditions such as chronic fatigue syndrome (35). In this model, pain is secondary to stress.

3. Pain experience has two components; sensory (intensity and localisation), and affective-emotional. In people with pronounced response to pain, emotional symptoms may dominate. Henningsen (36) describes fibromyalgia as a medically unexplained physical symptom with increased rates of depression and anxiety. McBeth et al (37) studied the association of tender points, psychological distress, and adverse childhood experiences and concludes that these factors can contribute to fibromyalgia. No references are made to studies on biological causes of pain and pain hypersensitivity.

Alternatives 1 and 2 can be present in the same patient.

Pathogenesis

For recent overviews of the pathogenesis of fibromyalgia see references 35, 38, 39. The main pathological changes in the nociceptive system in fibromyalgia are considered to be an expression of neuronal plasticity causing alterations in the function, biochemistry and structure of nociceptive neurons in the central nervous system (CNS). The changes caused by neuronal plasticity require longstanding bombardment of nerve impulses from the periphery on nociceptive neurons in CNS. It is probable that the pain stimulation must be intensive enough to activate the non methyl-d-aspartat (NMDA) receptors on the wide dynamic range neuron (WDR) in the dorsal horn of the spinal cord. When central sensitisation is established, even low-threshold stimulation, such as muscle tension in relation to mental stress or normal muscle activity, may elicit pain (38 for references, 40). Muscular changes such as disturbances in intramuscular micro-circulation and in muscular energy metabolism, which have been described in fibromyalgia, may be of importance both for the onset and maintenance of pain and allodynia (41,42).

The basal pain mechanism in fibromyalgia is pain hypersensitivity. When pain hypersensitivity is present, a number of different factors can evoke pain. These factors can vary from one person with fibromyalgia to another. In the same person, the peripheral cause of pain may vary from one location to another and from one time to another. Changes that may relate to neuronal plasticity in the spinal nociceptive neurons can lead to an augmentation of the impulses from the spinal neurons to the brainstem, basal ganglia, and cortex. This could

lead to a change in the function of descending tracts from the brainstem to the spinal cord neurons that in turn could lead to a change in balance between inhibition and facilitation. Whether decreased inhibition or increased facilitation (or both) give rise to the increased pain sensitivity is at present under discussion (43).

In individuals with normal pain sensitivity, pain can be inhibited by diffuse noxious inhibitory controls (DNIC), which means that pain in one region of the body can inhibit pain in another region. This inhibitory DNIC is dysfunctional in patients with fibromyalgia (44). During isometric muscle contraction, pain is inhibited in the contracting muscles. This does not happen in patients with fibromyalgia (45). While this could also contribute to pain, it is not specific to fibromyalgia, as it can also be observed in other chronic musculoskeletal pain conditions (see for example 46).

Why do all people with long-standing muscular pain conditions not get fibromyalgia? Predisposing factors may be the reason why certain individuals develop a pronounced decrease in pain thresholds (for references see 38). Being a woman increases the risk of developing fibromyalgia. Healthy women have lower pain thresholds than healthy men (47). Claw and Crofford (35) maintain that this fact is the main reason why more women than men are diagnosed with fibromyalgia. Sex hormones also affect pain sensitivity. Oestrogen has a pain-regulating effect and decreases pain. Low oestrogen levels may increase the risk of fibromyalgia (48). Further, people with a dysfunction in the stress regulation system may be at risk of developing fibromyalgia. Hereditary factors might also play a role.

Common symptoms in fibromyalgia

Longstanding, widespread pain is a characteristic symptom in fibromyalgia. The location of pain and the pain intensity in the body may vary from day to day as well as during the day (49). About one third of the patients have brief pain-free periods (50).

Muscular symptoms: the pain influences the ability to fully activate all motor units in a muscle, resulting in reduced muscle strength (51-53). The patients have problems with static and dynamic repetitive work, and muscle endurance is often diminished (51,52). On manual muscle testing, muscle strength is usually normal (54). However, patients with fibromyalgia produce about 50% of work during a maximal muscle contraction (55).

Sleep disturbances: deep sleep is affected, and most patients do not wake up refreshed (56).

Fatigue: pain, sleep disturbances, and stress may result in fatigue. Continuous pain causes stress, and the combined effect of pain, stress, and sleep disturbance could explain fatigue and cognitive disturbances, such as memory and concentration difficulties.

Neuro-endocrinological deficits: low levels of growth hormones and a disturbance in serotonin metabolism have been described in subgroups of fibromyalgia. Whether these changes are primary or secondary phenomena has not yet been settled (57,58).

Psychological symptoms: depression and anxiety are more common in patients with fibromyalgia than in the general population. Depression, anxiety and worries can be considered a consequence of the stress and consequence of the total impact of pain in daily life accompany longstanding pain. In a Swedish study (59) comprising 191 patients with fibromyalgia, 36% showed mild to moderate depression, and 35% of the women showed moderate to severe depression.

Long-term follow-ups demonstrate that some improvement can occur (60-62). Many patients with more severe symptoms and consequences are referred to specialty clinics. Thus, patients from specialty clinics may have more pronounced symptoms and more problematic consequences than patients in primary care (63). There is increasing evidence that patients with fibromyalgia who have had their symptoms for a number of years can be helped significantly with exercise, cognitive-behavioural training, and multidisciplinary programme (64). The ability to handle and cope with their altered life situation often comes after some time, described by Gullachsen (65) as life adjustment. The Life Adjustment model was formed after interviews with women in longstanding pain and describes how they pass through three stages with the aim of refocusing their lives on a new future. This personal adjustment to a new life situation must be taken into account when planning interventions for returning to work, as interventions at the appropriate time will increase the likelihood of motivation and a successful rehabilitation (65). Another important factor influencing the women's ability to cope with a changed life situation is the encounter between the women and the caregiver in health care. A qualitative study performed by Åsbring (66), including 13 women with fibromyalgia and 12 with chronic fatigue syndrome (CFS), shows that when the women were questioned and doubted, their identity were threatened. The women experienced such situations as deeply violating. A similar result was found in another study (67) of 40 women from the USA and Sweden. The women experienced the period before the diagnosis as very unconstructive. They felt rejected and disbelieved in encounters with health care personnel.

Consequences in daily life

Pain, tiredness, disrupted sleep, and muscle weakness, the major symptoms of fibromyalgia, have been shown to severely impact everyday activities (68-70). Patients report changed habits and roles in all areas of daily life, and since everything takes longer to perform and is experienced as strenuous, the time structure is disrupted (68). The studies show that the women find the variability in the severity of symptoms difficult when planning their daily lives. The majority of the women also report that they experience 50% or more of the tasks during the day as tiring or very tiring, and the majority of women need help with heavier household tasks. Leisure activities were also influenced, which means that the women have fewer recreational and social activities.

Further, the symptoms severely impact coping with a work role (67,71-73). Articles published showed that work disability due to fibromyalgia varies between 25% and 50% among patients with prolonged or chronic pain conditions (50,67,74,75). In a study performed by White et al (73) in 100 patients with fibromyalgia, 76 with widespread chronic pain (WSP), and 135 healthy controls without WSP, and matched with fibromyalgia for age and sex, it was found that the major effects on work capacity was fatigue, weakness, and memory and concentration difficulties. A logistic regression showed four variables for predicting disability: number of major symptoms, levels of satisfaction with health, number of tender points, and education level. Further, predictors for work disability are high scores on the impact of the syndrome, as well as unrestful sleep and physical stress in prior employment (73). Another study by Waylonis et al (76) shows that factors such as cold, prolonged walking, sitting, and standing aggravated fibromyalgia symptoms. These factors also appear in a Swedish study (68), in addition to work tasks such as carrying heavy loads, working with elevated arms, and holding tools. Studies performed in Sweden show that, in general, working women with fibromyalgia have shorter working hours (50,68).

The effect of employment and domestic work on health status was studied by Reisine et al (77) in 287 women with fibromyalgia and shows that the amount of time spent on domestic work was not associated with health status. Rather, it is the experienced psychological demands from the family, as well as the ability to control the pace of domestic work that affected the health status.

Quality of life

Quality of life is closely related to life satisfaction (78), and life satisfaction is closely connected to the ability to perform valued roles (79). Not being able to fulfil previous roles such as a work role has consequences for the women's experienced quality of life. Low levels of life satisfaction or quality of life may indicate that women with fibromyalgia have not managed to cope with the consequences resulting, from living with a chronic disease, by adopting new roles in order to be able go on with their lives. Several studies show that quality of life is experienced as low by people with fibromyalgia compared with those with other diseases such as RA, chronic obstructive pulmonary disease, and diabetes mellitus (80-82). In a study (83) performed in focus group interviews with 25 women, 18 with fibromyalgia and 7 healthy controls, the women were asked "What does the concept quality of life mean to you? ". From the interviews, four categories emerged as important for experiencing good quality of life: participation in society, being an active person, finances, and health. The women highlighted their work role as a major factor for being able to participate in the society, and experience a good quality of life (83).

Trombly (84) states that the meaning of occupation is so profound that people, at least partially, define life satisfaction as competent role performance. Bränholm (85) examines a person's values attached to certain roles in relation to perceived level of satisfaction and shows that roles associated with vocation, family life, leisure, and home maintenance correctly classify 62-78% of the subjects in terms of satisfaction with life. Usually, occupational therapists categorise roles into performance areas such as self-care, work, and leisure, which, according to Christiansen (86), is one way of classifying time. The classification of roles into occupational performance areas is important, even though the terms for these areas differ in the occupational therapy literature.

Time use and balance

The connection between time and occupation is fundamental to occupational therapy; people act in time, and time management is an aspect of occupying oneself within the values existing in the societal context (87). By investigating activities and the amount of time used in the different occupational domains, the occupational therapist can guide patients to explore new schedules of time use (87). This helps the therapist to understand the client's life style and experienced well-being (88). A need for balance between different occupations is recognised as a key factor to experience a state of health and well-being (89,90). However, Primeau (91)

and Wilcock (92) emphasise that since the occupational areas are culturally defined, they may not measure the balance in occupations. Primeau (91), emphasises the cultural dichotomy between work and leisure in assessing balance, and gives the example of parents playing with their children in the context of household work, thus combining work and leisure. Wilcock (92), on the other hand, suggests that occupational balance ought to be considered in terms of physical, mental, social and rest occupations instead of performance areas. A pilot study (92) was performed with 146 respondents filling in a questionnaire about their current balance of occupations, and their perceptions of the ideal balance. The respondents also filled in their perceived health. The results show a wide variation in current balance, whereas the ideal balance in occupations shows less variation. Almost 77% of the respondents chose an ideal balance as consisting of at least moderate involvement in all four categories: physical, mental, social and rest occupations. These results were also compared with the respondents' perceived health and show that the smaller the differences between current balance and ideal balance, the healthier are the respondents. Thus, the pilot study shows an association between health and ideal balance of occupations, although the concept needs to be studied further with a larger sample. Due to the cultural influence on definitions, Primeau (91) suggests, in measuring balance, that there is a need beyond the aspect of 'doing' to include the affective experiences that occur in a person's engagement in occupations. This would change the focus of the assessment of work and leisure from an activity-type definition, based on the activities a person engages in, to an assessment where the affective experiences are also included. Further, this would reflect the meaning of activities and the ability for the person to accomplish goals in life (90). Thus, this would also be an assessment of the balance of everyday occupations. Further, Cynkin and Robinson (93) point out that only individuals themselves can determine whether the number and variety of activities are appropriate and balanced for that specific person. They also maintain that experiencing balance will lead to a feeling of comfort and satisfaction with the activities of everyday living.

Aims

The purpose of Study 1 was to describe the work situation of women with fibromyalgia. No systematic studies had been done at that time in Sweden, and few in other parts of the world. Factors previously known from literature research to cause disability such as pain interference, concomitant symptoms, and type of occupation need to be investigated. This was

done by using quantitative methods and a questionnaire. It was also important to capture the women's own experiences and thoughts about which factors they felt had influenced their decisions to leave or remain in a work role. This information was gathered through individual, qualitative interviews.

- To identify factors of importance that enable women with fibromyalgia to continue working despite the limitations imposed by the symptoms (*I*).
- To examine which factors women with FM perceive as influencing their capacity to remain in a work role (*II*).

Most studies have been performed on middle-aged women. The purpose of Study 2 was to gain information from young, newly-diagnosed women with fibromyalgia about the difficulties and limitations these women encountered during their first year after diagnosis. This was done by using instruments and semi-structured interviews, with a special focus on employment and consequences for daily life. The study was performed both in Sweden and the USA, thus making it possible to investigate differences between the two countries.

- To describe the trajectory of employment loss during the first year after fibromyalgia syndrome and to determine variables that explain the loss of employment (*III*).
- To describe newly-diagnosed young women's own experiences of physical, psychological, and social difficulties during the first year after diagnosis; to identify factors that may increase or decrease their problems and to compare similarities and differences between US and a Swedish group on three occasions (*IV*).

The aim of Study 3 was to describe how the time-use and activity patterns in working and non-working women could be visualised and compared. A time-geographic diary method was used to discover how the working women prioritise among their activities in order to fulfil a work role. Methods need to be developed to gather more information about activity patterns and their influence on health. The time-geographic diary method was tested in a clinical setting in this study.

- To use the time-geographic method to investigate time use and activities in the daily lives of women with long-term pain and to use the method to encourage clients to make desired changes in their daily activity pattern (*V*).

Subjects

In all, 278 women participated. The characteristics of the samples are presented in Table 1. The women participating were diagnosed with fibromyalgia, except for one who had myofascial pain.

Table 1. Background data on women with fibromyalgia participating in the different studies.

	Study 1 <i>Paper I</i>	<i>Paper II</i>	Study 2 <i>Paper III</i>	<i>Paper IV</i>	Study 3 <i>Paper V</i>
Subjects, n	176	39	94	94	16
Diagnosis	FM	FM	FM	FM	15 FM, 1 myofascial pain
Age, yrs, mean, SD, (range)	47±9 (20-64)	49±8 (26-64)	32±5 (18-39)	32±5 (18-39)	37±8 (20-50)
Duration of symptoms, yrs, mean, SD, (range)	12±7 (3-40)	14±10 (3-40)	6±6 (0.5-22)	6±6 (0.5-22)	8±6 (1-18)
Time since diagnosis, yrs, mean, SD, (range)	3±3 (0.5-16)	4±3 (1-11)	≤0.5	≤0.5	1±1 (0.5-6)
Employed, hrs					
48-20	26	10	35	35	4
19-10	62	9	8	8	4
Education, yrs					
9	81	16	26	26	3
12	57	10	49	49	10
University	34	13	19	19	3
Missing data	4	-	-	-	-
Family, n					
Married/ Cohabiting	137	29	64	64	13
Single	39	10	30	30	3
Children, living at home	79	21	62	62	12

Of all the women in this thesis, 48% were working outside their homes. The different occupational areas where the women currently work or have previously been employed are in Table 2.

Table 2. Classification of occupation according to the Swedish version of the International Classification of Occupation (ISCO,1986). The 278 women have been divided into a working and a non-working group, in which previous occupation has been recorded.

Classification of Occupations	Working, n= 133	Non-working, n= 145
Management, leadership	8	2
Theoretical specialist competency (e.g., dentist, teacher)	23	12
Short academic education (e.g. preschool teacher, recreation leader)	17	15
Administration, customer service	24	56
Service, care, and business	30	46
Farming, gardening, fishing, forestry	1	1
Craftsmen, artisan, handicraft	5	2
Processing, machine operator, transport	10	11
Work without formal vocational training (e.g., cleaner, catering assistant)	10	13
Student	5	
Missing	0	7

Inclusion criteria

Study 1

In *Paper I* a consecutive sample of case notes of 288 persons with fibromyalgia seen at tertiary health care clinics were included. Inclusion criteria were: a fibromyalgia diagnosis with no other diseases, age 16-65 years, and female. The inclusion criteria excluded 70 persons, leaving the remaining 218 women in the study. Only the participant's identification and diagnosis were drawn from the case notes. Figure 2 shows a flowchart illustrating the design and the women participating in Study 1.

In *Paper II* a purposive sample was drawn from the 160 women who participated in the previous study and had agreed to be contacted again in the questionnaire. The purpose was to select 20 women who were still working outside their homes, and 20 who had left the labour market. The women were divided into working or non-working groups, and chosen from various ages, different types of occupations, and different numbers of working hours. Forty-eight women were contacted by telephone. Three declined to participate, and five of the

women in the working group had stopped working since the previous contact and thus did not fulfil the inclusion criteria. Of the remaining 40 women, one no longer fulfilled the ACR classification criteria for fibromyalgia at the physical examination and was therefore excluded from the study. Thus, answers from the interviews included 39 women; 19 still in paid work and 20 who had left the labour market and were on sickness leave or had disability pension.

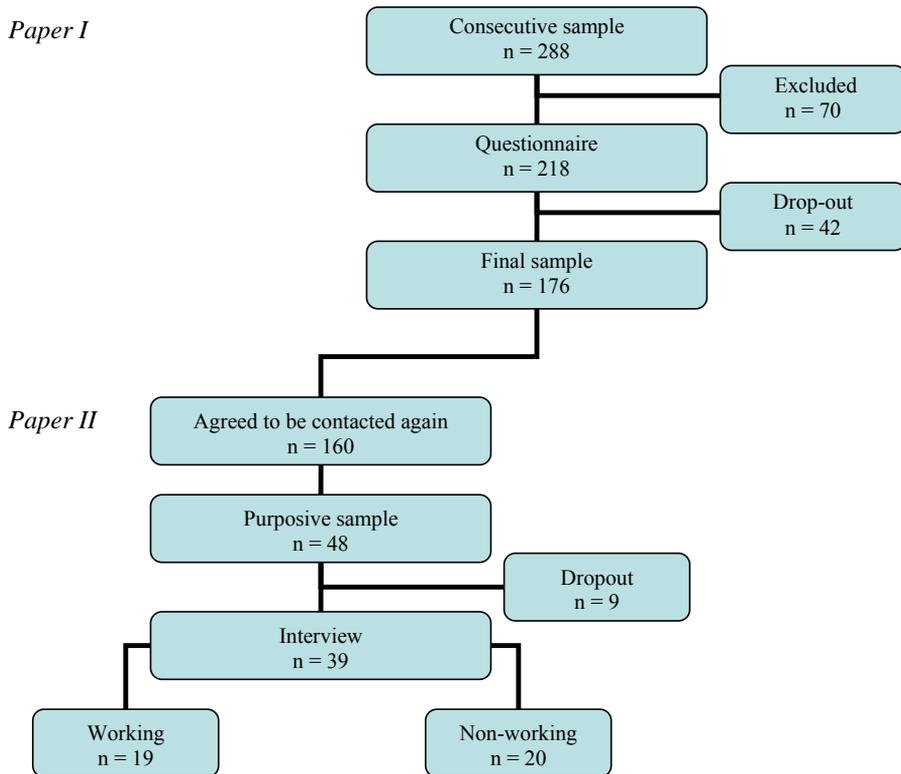


Figure 2. Flowchart illustrating the design of Study 1, and number of participating women.

Study 2

In *Papers III* and *IV* women were informed and asked to participate in the study in connection with a scheduled visit to two university referral clinics in the United States or Sweden and one regional hospital outpatient clinic in Sweden, a convenience sampling (94). The inclusion criteria were: meeting the diagnostic criteria for fibromyalgia, 39 years or younger, and diagnosed with fibromyalgia at the time of the first interview or within the previous six

months. In all, 49 women from Sweden participated - 28 from the university pain clinic and 21 from the regional hospital clinic - and 45 from the United States.

Study 3

An accidental sample (95) was used in this study. Eight women who participated in Study 2 were informed and asked to participate in this study. Six were asked in connection with entering a rehabilitation programme for people with longstanding pain, and two were asked by a physician in the university referral clinic. All the women fulfilled the criteria for longstanding pain; 15 had fibromyalgia and one myofascial pain.

Ethics

The studies in this thesis have been approved by the Research Ethics Committee, Faculty of Health Sciences, Linköping University. Study 2 has also been approved by the institutional review board of the Oregon Health and Science University, Portland, USA and the Research Ethics Committee of the Faculty of Medicine, Uppsala University.

The women were informed about the content of the studies in an introductory letter and asked to participate. In Study 1 the women gave written consent to be contacted again, and in the other studies gave written consent to participate. Written information was presented to the participants to enable them to voluntarily decide whether or not to participate in the different research studies. Efforts were made to write the information in a language that could easily be understood by the participants. Confidentiality was assured.

Physical examination by medical specialists was performed in order to confirm the diagnosis, and the women were informed that the pain might increase after the examination. In all informed consent documents the responsible research personnel were presented with names and telephone numbers, which gave the participants the opportunity to ask questions, before, during and after the project. It was emphasised that withdrawal at any time, or a refusal to participate in the study, would have no effect on ongoing or future treatment.

Methods and procedures

Both inductive and deductive approaches were used since the questions required different methods. The inductive approach was used when data needed to be analysed and understood from the women's perspective in order to achieve new or deeper knowledge about a phenomenon. Interviews and diaries were used. The interviews were analysed using a qualitative approach and a content analysis method. The diaries were analysed with both quantitative and qualitative approaches. The deductive approach was used in questionnaires and instruments when the aim was to describe, analyse and predict certain phenomena in women with fibromyalgia.

Study 1

In *Paper I* a descriptive, cross-sectional design was used, and a mail questionnaire (Appendix) was sent out. The questionnaire was designed to collect demographic data, data about the fibromyalgia condition, and data about the work situation. In addition, information on satisfaction with the global life situation, type of occupation, and present work tasks were gathered. In the questionnaire the women were asked whether they might be contacted again; 160 agreed. Finally, a pain mannequin was used to investigate the location of experienced pain "during the past week".

In *Paper II*, in combination with a tender point examination performed by a physician at a pain clinic, a pain mannequin was filled in by the women. Individual interviews were performed with a focus on the factors the women themselves regarded as important for facilitating or hindering their retention of a work role. An interview guide was used to ensure that certain areas were discussed, such as: present or previous employment; adaptations in the workplace; additional responsibilities; the value attached to work; personal strengths and weaknesses as workers; and, finally, opinions about future work.

Study 2

In this study, a longitudinal, descriptive/correlational design was used. Data were collected by interviews and self-administered questionnaires three times, six months apart.

At the interview, data were collected concerning demographics, the fibromyalgia condition, work situation, sickness absence, treatments, physical exercise, and strategies used to diminish symptoms and difficulties.

The women filled in the following self-administered questionnaires:

Fibromyalgia Impact Questionnaire (FIQ): The FIQ measures the impact of the syndrome and includes questions on physical function, symptoms, the interference of pain with work, sick leave, and the number of days the person felt well during the previous week. Each item is standardised on a scale of 0-10 points (96). A higher score indicates greater impact. The Swedish version of the instrument has been validated (97).

Shortform Health Survey (SF-36): The SF-36 measures health status in eight domains: physical functioning; role physical; bodily pain; general health; vitality; social functioning; role emotional; mental health (98). The scale ranges from 0-100, where a higher score indicates a better health status. The Swedish version of the SF-36 has been validated (99).

Beck Depression Inventory (BDI): The BDI contains 21 items that measure mood and the physical symptoms of depression (100). The BDI has been validated in Swedish (101). The adapted version (BDI-A) for fibromyalgia patients has been used in this study (102). Scores range from 0 to 54, and a higher score indicates more depressive symptoms.

Beck Anxiety Inventory (BAI): The BAI contains 21 items that measure physiological and emotional symptoms of anxiety and discriminates symptoms of anxiety from those of depression (103). Scores can range from 0 to 63 with the higher score indicating more anxiety. The scale was translated into Swedish for this study.

Yelin Scale of Job Flexibility: This is a 5-item questionnaire asking the participant to assess work autonomy concerning adjustments of work hours and the possibility to take time off from work. The response alternatives given are that it can be “done independently”, “done by telling a supervisor”, “done by asking permission” or “cannot be done at all” (104). A higher score indicates less flexibility. The scale was translated into Swedish for this study.

Social support (AIMS II): This is a 5-item subscale of the Arthritis Impact Measurement Scales II (AIMS II) (105). A higher score indicates more social support from family and friends. The instrument has been validated in Swedish (106).

In *Paper III* the employment status of the women and the results from the instruments are presented.

In *Paper IV*, five open-ended questions were asked concerning the women's perceived limitations and difficulties in their daily life. The open-ended questions in the three interviews were:

- 1) What, if any, physical difficulties or limitations do you have because of fibromyalgia?
- 2) What, if any, psychological difficulties or limitations do you have?
- 3) What, if any, social difficulties or limitations do you have because of fibromyalgia?
- 4) What increases these difficulties or limitations?
- 5) What decreases these difficulties or limitations?

At interview 2 and 3 the women were also asked:

- 6) Have you found any ways to prevent the difficulties or limitations that you have experienced related to your fibromyalgia?

Study 3

In *Paper V*, a longitudinal descriptive cohort design was used, with a time-geographic diary method. This is a qualitative method to study time use, and to describe activity patterns and the complexity of daily life (107). The time-geographic approach illustrates and observes, in a systematic way, how circumstances in time and space exert restrictions and put limits on the ways people live their lives. The time-geographic diary method has been developed to enable clients themselves to scrutinise and actively improve their way of life. The diary rests on the belief that to succeed in making changes in their lives, individuals must be conscious of their situation, and have the opportunity to take responsibility and the ability to act. A greater awareness of one's life situation may lead to an increased feeling of control in life (108). The method can be used in studies of the everyday life of individuals as well as with groups and at societal level (109). It differs from ordinary time-use approaches as this specific method makes it possible to observe how the activities are related to each other, to investigate how the activities constitute meaningful parts in the individual's life context (projects), and to consider

the individual's intentions behind the activities performed (107-109). Since the activities and activity changes are in focus, and determine the time documented by the women, the diary gives a picture of activity-related time (109).

A notebook, used as a diary, was prepared with the headings: time, activities, location, with whom, physical problems, and mood. The diary was filled in during seven consecutive days during the first period and during four consecutive days in the second. The number of total days analysed amounted to 174. A questionnaire was used to gather data on age, family, education, employment, sickness benefits, duration of symptoms, time since diagnosis, and pain characteristics. The flowchart over the time period and procedure is presented in Figure 3.

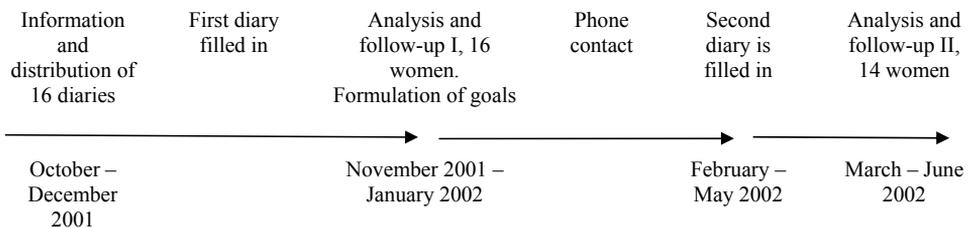


Figure 3. Flowchart of the process in Study 3.

Quantitative analyses

In all three studies, descriptive statistics were used to present demographic data. For non-parametric data, the Mann-Whitney U scale and the chi-squared test were used to test between-group differences (110) in *Papers I* and *V*, and Student's t-test in *Paper V*. Cronbach's alpha was used as a reliability test (94) to ascertain internal consistency in translated instruments in *Paper III*.

Multivariate analyses (111) were used in *Papers I* and *III*. In *Paper I*, two manual logistic regression analyses were performed, one with the women divided into working (n=88) and non-working (n=88) groups, and the second performed with the working group (n=88), and the women not-working because of fibromyalgia (n=41). In *Paper V* backward stepwise logistic regressions analyses of demographic and personal factors associated with employment were performed, at the initial interview, after 6 months, and after 12 months. A

listwise deletion of cases was made before doing the regression to eliminate any cases in time 2 or time 3 that did not have complete data for the entered variables.

The significance level, set at $p < 0.05$, was two-tailed in all studies, unless otherwise indicated.

Qualitative analyses

In *Paper II* an inductive analysis was performed (112), meaning that the categories presented emerged from the interview material. The analysis was done in three steps. First, each interview was read several times to form a general impression. Then each interview was read and identified by coding notes to structure the text into units. The notes were finally classified into subcategories and compared to investigate similarities and differences, building up the main categories. The category system was finally tested for its completeness (113), meaning that internal (consistency within categories) and external plausibility (the categories comprising the complete picture) should be achieved. Categories must cover the illustrated problem, and the categories should be reproducible.

In *Paper IV* the answers from the open-ended questions were analysed with a content analysis approach. Content analysis (CA) can be regarded as either a quantitative or qualitative method (114). In this study, the approach was qualitative. The CA method was used to be able to compare and contrast groups and to investigate trends over time (114). Answers to each question were divided and marked into units. The units were collected into subcategories, which were added to form categories. Thus, categories were formed under each question, and the questions posed guided the analysis. Each subcategory was used only once per woman, was added in frequencies, and presented in proportions.

In *Paper V* the diary was first coded according to a special coding scheme developed for the diary method (115) and entered into a computer program, to calculate time from different areas and to create graphs. For physical problems, moods, and social relations, individual codes were computed for each woman, since these contained the women's own words and descriptions. The codes were summarised into categories using a qualitative approach. The authors discussed the interpretations and categories to assure the trustworthiness of the results.

Results

Study 1

In *Paper I* the questionnaire study is documented. The final response rate was 81%, or 176 women. Of the women participating, 50% were employed. Seventy-seven of the working women stated that symptoms affected their work ability, and 61% were blue-collar workers. The women reported that some work tasks were difficult to manage, such as lifting and work with elevated arms. The work situation had been changed for 58% of the working women, and 80% counted on being able to continue working. Of the non-working women, 87 had previously been employed. Reasons for not working were reported as being related to their symptoms by 41 women. Thirty women considered impossible to remain on the labour market despite more suitable work, but 7 women explained that they could have remained if a more suitable work had been arranged. Patients in the working group had significantly lower values than the non-working women in “abnormal tiredness during the day”, and “gastrointestinal symptoms”. On the question of satisfaction with the present situation, the working group was significantly more satisfied than the non-working group.

Paper II presents results from the qualitative analysis. Four categories appeared that the women considered important for remaining in a work role. Categories were found at societal level (values and norms, and structural factors in society), as well as individual level (working conditions, and other commitments). The meaning of work was expressed in terms of “having an identity”, “feeling valuable”, and having an opportunity for “social contacts”. Work was also stated as an important part of an organised time structure. The continuous restructuring and changes in the labour market were mentioned by the women as complicating their work situation and resulting in less flexibility concerning work schedules and work tasks. Working conditions, including the physical work and psychosocial environments, were important for the women in remaining in their work role. Factors such as the ability to use varied postures and being met with understanding from both employers and work mates were considered important. Unpaid work, such as responsibility for domestic duties and taking care of children and older relatives, also influenced the women’s ability to remain in their work.

Study 2

Results from this study are presented in *Papers III* and *IV*. At the first interview, within 6 months of the diagnosis, 46% of the women were working (USA 56%, Sweden 37%). Since the time of diagnosis, 13 women had left the work force. All had done so because of problems related to fibromyalgia. At 6 and 12 months later, 41% were working. The women who remained employed were older, perceived considerably less difficulty in daily activities, experienced lower severity of symptoms, especially pain severity, and pain interfered less with their ability to work. Thus, factors predicting unemployment were younger age, lower physical functioning and self-efficacy in pain management, along with higher symptom interference and pain severity.

In *Paper IV*, the analysed open-ended questions, asked on 3 occasions and involving 94 women, resulted in categories such as symptoms, movements and postures, and activities. These reflected the physical difficulties experienced by the women. Psychological difficulties, such as irritation, tearfulness, and frustration and depression were common among the women. Further, concentration and memory difficulties, and exhaustion emerged as subcategories. The women mentioned social difficulties such as a limited social network, fewer activities, and the feeling of not having the strength for a social life. The difficulties mostly remained over time. Both Swedish and American women stated tiredness and sleep disturbances as factors that increased their difficulties.

Study 3

Paper V represents the results from Study 3, and shows that all the women used time in all the different activity spheres except for “gainful employment”. The results showed that working women used significantly less time on ‘Care for others’, ‘Care for oneself’, Rest, and ‘Procure & Prepare food’ compared with non-working women. Further, working women used time in a manner similar to that of the general Swedish female population. The number of times activities occurred during the day varied. In the total group, the mean number of activity occurrences was 27, with a range from 10 to 65. The women reported physical problems such as pain, stiffness, tiredness and tenderness during a mean of 14 hours each day: the working women, 11 hours, and the non-working women, 16 ½ hours. In the questionnaire, the working women tended to be more satisfied with their global life situation.

Discussion

Methodological considerations

Participants

All the women in this thesis were examined and diagnosed according to the ACR criteria (24) at a specialist clinic in university hospitals or at a rheumatology clinic in a regional hospital. The women had all been referred to speciality clinics, which may imply that the women had more pronounced difficulties compared with patients at primary care level (63), and may thus represent more disabled people than can be expected in a general fibromyalgia population. The women included in *Paper I* had been diagnosed a few years before the study and improvements may have occurred during the time since diagnosis. However, follow-up studies (63, 116) show that fibromyalgia is a stable condition over time. Additional diagnoses were excluded from the sample, thereby limiting the influence of potential confounding variables (94). The women varied in age (18-65 years), degree of employment (part-time and full-time), occupations, and other sociodemographic data. In total, they were somewhat younger (mean age 39 years) than women in other studies investigating the impact of fibromyalgia on daily activities, where the mean age is 44 (50,67-70). Further, in Study 2 the women were somewhat younger than those in Studies 1 and 3. Thus, our findings show how fibromyalgia impacts younger women's lives and additional commitments such as having small children living at home. This might affect the results, and show a worse situation for these women. The more demanding family situation was related to women on sick leave, and may be one explanation for their inability to manage both family and employment. However, the results must be generalised with caution, since the samples are small.

In *Paper III* and *IV*, the women represented two countries. There were differences concerning the number of women who remained in work, most likely as a consequence of the different social systems in the two countries. However, in other aspects such as symptoms and consequences for daily life there were similarities in the difficulties reported.

Quantitative methods

Cross-sectional and longitudinal designs were used in this thesis. Cross sectional design (Study 1) offers a picture at a specific time in the women's life, and results must be interpreted with caution since symptoms and other factors influencing the ability to remain in

work fluctuate over time. The design of the longitudinal studies is a strength (Studies 2 and 3); they were prospective and made comparisons over an extended period, 1 year and 3 months, respectively, and allowed investigated outcomes to be measured over time.

Combining methods of analysis can give a deeper understanding of a phenomenon and may also serve as a way to triangulate and thus strengthen the results (113,117). In this thesis, Study 1 and Study 2, in particular, were designed by using both quantitative and qualitative methods to describe a phenomenon from different perspectives so as to measure prevalence and frequencies of known and to phenomena and to capture the women's own subjective experiences.

The postal questionnaire in Study 1 was developed to collect data in *Paper I*. The face and content validity was supported by discussions in a research group and factors known to cause disability in fibromyalgia, such as work tasks, work postures, and how strenuous the occupation was.

All instruments used in Study 3, except two, had been tested earlier in their Swedish versions. The instruments translated to Swedish for this study were the Beck Anxiety Index (BAI) and the Job Flexibility Scale. They were translated to Swedish and back-translated. The internal consistency reliability was .84 (Job Flexibility Scale) and .88 (BAI), a level of homogeneity that must be considered good. The correlation of the BAI with the anxiety item (.49) from the Fibromyalgia Impact Questionnaire was acceptable, since the BAI represents symptoms not necessarily associated with anxiety such as face flushes, sweating (not due to heat), and trembling hands.

The Job Flexibility Scale (104) measures autonomy at work. However, in this study the instrument might also have been shown the differences between the Swedish and the US work environment regulations. Working hours and opportunities for leave of absence are clearly regulated in Sweden, and this was probably why the scale did not have any predictive value between work autonomy and future job loss. It has been shown that the ability to influence *what* to do and *how* tasks are performed at work is more closely related to a feeling of control and a better health status. Therefore, another instrument should have been used, such as the demand/control/support instrument in this study (118).

The sub-groups in the different studies were sometimes quite small, and normal distribution of the data could not be assumed to exist. Therefore mainly non-parametric analyses were

considered the most suitable. Further, in addition to the ordinal scales of the instruments, non-parametric analyses were mainly used, except for the regression analyses performed in *Papers I and III*.

Qualitative methods

Interviews are well suited to capturing peoples' experiences and thoughts in a specific area (119). Therefore they were used in *Paper II* to investigate the women's own experiences of factors facilitating or hindering their ability to remain in a work role. An interview guide was used to guarantee that certain areas were discussed. An opening question, "Tell me about your present/earlier work situation?", was used in the beginning of the interview, but as the women directed the interview, no two interviews were alike. Using a non-standardised approach in interviews makes it easier to probe and to achieve more substantial answers from the women (112,119). The interviewer was not involved in health care and treatment, thus, the participants were not in any state of dependence.

The sample used in *Paper II* may be considered large for a qualitative study. It was a purposive sample, selected to make it possible to gather varied opinions. The sample consisted of two groups, working and non-working, which is one reason for its size. Further, since the interviews were performed only once, it was considered valuable to increase the sample. This may also strengthen the validity of the results, and enable them to be transferred to other settings (120). A method commonly used in qualitative research to validate results is to let the informants verify the result (112,121). In this study respondent validation was not considered relevant by the authors. Rather, the material was validated by a co-worker reading and confirming the categories that emerged.

In *Paper IV*, semi-structured interviews were performed, in which the women responded to direct, pre-formulated questions. No additional questions were posed. The content analysis (CA) used in this study was qualitative, considering that the categories were grounded in the material and not classified in predetermined codes. Counts in qualitative CA represent a summarisation and localisation of patterns appearing in the material (121,122). Notably, this material was not grounded on completely open questions. The questions asked indicated that we already knew that there were difficulties in the physical, psychological and social areas. According to Morgan (122), this strengthens the construct validity of the CA. Such a method of counting frequencies of statements made it easier to compare the Swedish and American groups and detect patterns that differed. However, the aim of this study was not to find

statistically significant differences, in which case predetermined codes and a quantitative CA would have been chosen (114,122). In the interviews the women answered the questions most likely naming the physical, emotional and social factors that occupied them most on that specific occasion. No check was performed for specific factors, and some of the women may have forgotten to mention some. Thus, the results must be interpreted with caution, so statistical analyses were not considered as relevant. The importance of caution in interpreting statistics when using non-standardised questions in a non-representative sample is described by Malterud (120). The validity of this study is strengthened by comparing previous research, as described by Downe-Wamboldt as a method of judging validity (123). It was shown that previously known factors, experienced as problems, also appeared in this study, although with another frequency.

In *Paper V* the diary method was used primarily as a time-study method, although the follow-ups with the women made it possible to evaluate changes in their lives. The diary used did not show the proportion of time spent on occupations that were valuable for the women. If the value of activities is of importance, the method could be supplemented either with importance scales or more direct interviews where qualitative data concerning the value of different activities can be obtained (124). This could also have been achieved with a focus in the study on changes in activity pattern over time instead of actual time used on activities. This method was validated by the women themselves, scrutinizing their graphs and giving their own opinions about the extent to which goals had been fulfilled over time. The graphs of the days started a process of reflection on the women's daily lives and activities, as they give a clear picture of which activities are performed during the day. By using this method in rehabilitation, people can gain insight into and an awareness of how they live their daily lives. Some women recognised themselves in the graphs, whereas others were not aware that they spent their days in the manner shown by the graphs. Diaries are one way to actively work with necessary changes in activity patterns to better cope with daily life. However, time for coding and computing must be simplified if this is to be used in rehabilitation.

Discussion of results

Only women were included in this thesis. One reason for this was that the fibromyalgia population consists of 90% women and there is a need to obtain more knowledge on the specific conditions that women have. Another reason was the development of the illness and the progress of treatment and rehabilitation. Thus, a women's perspective is used in this

thesis, but with attention to the diversity of living conditions and the variety of opinions presented by the women. However, women and men, as a consequence of a gender order, live under different conditions, have different experiences, and use different strategies because of social, cultural, ethnic, and political circumstances, and the biology (125). The gender order exists in all human societies, and is present at individual, organisational, and the cultural levels. Gender relationships are also influenced by other circumstances, such as age, social class and ethnicity (126). Focusing on women only has been important for the research presented in this thesis even if no explicit gender theory has been used as an analytical tool. It became obvious that gender-related experiences were important reasons that contributed to the difficulties for the women to remain in a work role.

Factors hindering or facilitating a work role

The results showed that the majority of the women who were still working outside their homes had changed their work situation. One solution had been to change occupation. In the newly-diagnosed young women, more American than Swedish women had changed their occupations. The reason for this may be that they were unable to keep their job when on sickleave and were thus forced to try to find solutions of their own. This shows the impact of different social systems in the two countries. Of the non-working women in this thesis, 87% had previously been employed in administration, service and care, processing, and work without formal vocational training. These jobs are characterised by static, repetitive, and heavy work tasks, and represent areas where the risk of musculoskeletal disorders is high (5). The jobs were obviously not suitable for women with longstanding pain, and may have contributed to the development of fibromyalgia. It is also known from previous research that sickness absence in women is higher in gender-segregated jobs such as those described above (16), which might also be a contributing factor for not remaining in the work place.

A reduction in work hours was usually required to be able to continue working. This, however, was not possible for single women, especially mothers. Their wages were their only income and, since many of the women had low salaries, they considered a reduction in work hours as unfeasible. In the interview study (*Paper II*) the women described how constant rationalisation and restructuring in the labour market had complicated their work role. Either the pace of work was increased or they had had to change position, which involved more demanding tasks or movements and thereby greater pain. This contributes, according to the women, to the difficulties of maintaining a work role. Bildt and Michélsen (7) show that

increased demands for flexibility to match production demands, and being employed as temporary staff, are harmful to the mental health of the working female population in particular(7). The women who were still working (*Paper II*) also expressed their worries about being able to remain in the labour market in the future with the constant changes and increased stress. A lower control increases stress and aggravates symptoms, which contributes to not being able to remain at work. Lannerheim (127) shows that the most demanding factor for middle-aged and elderly women in the labour market is the constant worry about being able to keep their jobs, interpreted as limited control over their work situation. The result in *Paper II* shows that the women, in addition to their illness and disease, were also influenced by structural changes in society such as economic recession and work restructuring, which makes it more difficult to join the labour market. Another structural factor described by the women as an additional strain on their life situation (*Paper II*) was the distance between work and home. For people with constant pain commuting is strenuous and time-consuming. It can aggravate the total life situation for the women and limit their ability to remain in the labour market.

Another way to remain in an active work role was to change work tasks. Results in Study 1 showed that static and repetitive work increases pain and should thus be avoided. But the difficulties of changing work tasks to less demanding ones was reported by the women in the interviews in *Paper II*. They also found it hard to ask workmates for help and assistance, as everyone experienced the work load as high. The women in this thesis were mainly employed in occupations that were difficult to adjust for people in general, and especially those with pain conditions. Many women emphasised the importance of changing work tasks, but since most of them worked in sex-segregated ie female-dominated occupations, the possibilities were limited due to a less diverse labour market.

The women also pointed out the importance of direct support from employers and from workmates, and the need of an understanding attitude from personnel in their work environment. In *Paper V* the diaries showed that the women on sickleave did not have any contact with employers or workmate. This was also a found in the interview study (*Paper II*), where the women described their lack of support in returning to work. The importance of a constant contact from the employer during sickleave is reported in a study by Nordqvist et al (128), where the respondents regard this aspect as a promoting factor in return to work. The working

women (*Paper I*) had usually been with the same employer for many years, knew the work tasks and the work place well, which made it easier for them to remain in work.

Further, the results showed that it may be necessary to redistribute tasks in a family in order for women to be able to continue working outside home. Some of the working women emphasised the importance of having a supportive family. They had been relieved of the pressure of the total responsibility for household chores and were thus able to continue working outside the home, or to keep up their social activities. Other women reported that taking care of the family was all they could manage, and they could not see any way to manage both employment and domestic duties. One reason why the non-working women did not manage to remain in the labour market could have been that they had a more demanding family situation than did the working women. They had more, and younger, children and spent significantly more time on caring for others, and in procuring and preparing food as shown in *paper V*.

Frankenhauser reports that women have the main responsibility for childcare and for most household duties, as well as having a higher number of working hours in the home than men. The total work load also increased significantly with the number of children living at home (129). It became clear in this thesis that these gender-related experiences contributed significantly to the difficulties experienced by the women with respect to remaining in a work role.

The total life situation, including family life, was of importance and impacted the women's ability to cope with a work situation. In a study of women with fibromyalgia, Reisine et al (77) show that the amount of hours spent on domestic work is not associated with health status. Instead, the psychological demands experienced from the family, and the diminished ability to control the pace of family work, have a strong effect on health status and are associated with lower health status.

However, how the women's symptoms influence their situation must also be regarded from a medical perspective. The non-working women, in all studies, showed a generally worse picture of symptoms: more pain, stiffness, tenderness, sleep disturbances, and tiredness. This may explain their inability to work outside the home. The intensity of pain in fibromyalgia is high and fluctuates over the day, and from day to day. It impacts physical capacity and increases fatigue. The presence and interference of the symptoms were also shown in the newly-diagnosed women (*Paper III*), and especially fatigue and morning tiredness were rated

high. Symptoms and their consequences as reported by the women in the interviews (*Paper IV*), did not increase during the first year. The coping strategies learned and used over time by the women can explain the rather stable condition. Strategies such as alternative ways of doing things, fewer activities and a slower pace may have prevented their condition from becoming worse. This hypothesis is supported by a study performed by White et al (2) following newly-diagnosed women with fibromyalgia over three years to determine whether the diagnosis in itself has a significant effect on factors such as health status and function. The result showed that although the women appeared to become somewhat less active in their life, satisfaction with experienced health improved, and their symptoms decreased over the three years.

Most of the job loss (*Paper III*) was associated with fibromyalgia symptoms. The symptoms and consequences are similar to previous studies investigating the impact of fibromyalgia on daily activities (48,62-65). In *Paper I*, abnormal tiredness was reported by 69% of the women, and the interviews (*Paper II*) showed that tiredness is a greater problem in the women's work situation than pain. The presence of morning tiredness and fatigue is also reported as high in *Paper III*. This may be a natural consequence of sleep disorders, as the presence of pain leads to sleep disorders and depression, which in turn predict fatigue (130). According to Wolfe et al (131), it is six times more common that women who report fatigue are unable to work. Thus fatigue is a strong predictor of work dysfunction and an overall lower health status.

A rapid increase in sickness absence in the percentage of young newly-diagnosed women with fibromyalgia was seen in Study 2. One explanation may be the fact that some of them did not have a work place to return to. This would make the return to the labour market more difficult. For women with short education, the chances of finding suitable employment diminishes. The risk of long-term sickness absence and, eventually disability pension must be regarded as higher for these women. However, Wigers (132) show that disability pension predicted a worse outcome in respect of pain, pressure tenderness, lack of energy, and work capacity. And for many young women, a long sickness absence or pension is not the best way to attain an acceptable health status and good quality of life.

Time use and balance

The results of all the studies confirm that fibromyalgia symptoms seriously impact the women's lives in areas such as work, leisure and domestic care. As shown in *Paper V*,

symptom interference was present in working women during a mean of 11 hours per day, and non-working 16 ½ hours per day, which led to a disrupted time structure, where everything took longer to perform. That can have consequences for the women's ability to perform previous roles. Roles are connected with specific habits and tasks, and it may be difficult or even impossible for the women to perform them any more. The women also need breaks and pauses in their activities, which means that more time is needed now than before, and the women have to prioritise between activities that previously were so self-evident for them. The diary method in Study 3 showed many activities during the days for both the working and non-working women. In this thesis, many interruptions are interpreted as means of coping with the situation. Pauses and breaks are necessary so as not to increase the pain and to make it possible fulfil activities. Studies investigating healthy women's activity patterns show that many interruptions in daily activities were associated with a sense of low control during these activities (133). Further, the occurrence of many activities during a day was associated with a lower self-perceived health (134).

Non-working women were less satisfied with their life situation than working women (*Papers I and V*), which could mean that the working women were either healthier than the non-working women or that their ability to retain a work role was of vital importance. The women expressed factors such as having an identity, feeling valuable, and meaningful participation in society in describing the value of work (*Paper II*). This identity was threatened when the women left the labour market, and the loss of a work role led to a feeling of being an outsider. This impacted their self-esteem and their experienced quality of life. When a return to the labour market is not possible, the women may be helped to reorganise their lives and find suitable interests that they can manage in order to experience life satisfaction. The inability to fulfil valued roles and activities may also lead to diminished life satisfaction and well-being. In an Australian longitudinal survey on women's health, the relationship between role occupancy (worker, partner, parent, student, and caregiver), health, and well-being was explored. The middle-aged women with none of the defined roles had lower levels of health and well-being, even after adjustment for chronic illness and sociodemographic variables (135).

In this thesis, the women had to prioritise between previously performed activities. Their time structure was in disorder since everything took longer to perform. It was important for the women's sense of well-being to reorganise their lives and still feel life satisfaction. A less

meaningful life situation may also lead to greater focus on their own health problems. Occupying a work role may diminish the ability to fulfil roles in the home and in social life. Similarly, demands in the home, self-imposed or by the surroundings, may diminish the ability to return to work. A balance, as experienced by the individual between work, leisure and domestic work must be accomplished. Thus, the women must experience that the roles they wish to fulfil correspond to their needs, such as remaining in the labour market. In addition, depending on their capacity, they require adjusted work tasks and manageable work hours to achieve good life satisfaction. When assessing the balance in the women's daily life, it is of importance not only to investigate activity areas and the actual time spent in those areas, such as work, leisure and domestic work, but also to investigate how the women value these activities (89, 90). This will reduce the cultural differences that might exist between therapist and patient in assessing time use. In order to achieve the best possible health experience, it is important to help these women find a balance in their daily activities.

Conclusions

- Most women with fibromyalgia are limited in their ability to work. Despite such limitations, 48 % of the women in this thesis were employed; 62 worked 20-40 hours per week, and 71 worked 10-20 hours per week.

- The results indicate that when individual adjustments in the work situation are made and the women find a level that matches their ability, they continue to work and find satisfaction in their work role. Further knowledge of how to take advantage of partial work ability is of importance for society and the individual.

- Many important factors, besides degree of impairment or disability, influence whether patients with longstanding and disabling conditions remain in the work role or return to work after sickness leave. The total life situation, other commitments, type of work tasks, ability to influence work situation, and the physical and psychosocial work environment are important factors in determining whether a person can remain in a work role.

- Both the physical and psychosocial work environment should be evaluated in assessing the women's ability to return to work. This implies that the administrative and supervisory staff at the work place often need to change prevailing attitudes, values, and behavioural responses with respect to people with work disabilities.
 - It is essential to evaluate the women's situation at home in relation to their responsibilities for tasks in the family. Tasks in the family may need to be redistributed.
 - Further, structural factors in society concerning the labour market and unemployment levels must be considered. Structural reorganisation and the accompanying faster pace of the labour market have affected women in general, and probably to a higher extent women with functional limitations.
 - The extent to which women commute also needs to be considered and added to the total situation and the working hours.
 - The rapid increase in sickness absence of young women with fibromyalgia is an important finding. This should be further investigated.
 - If the work situation is not adjusted as required, longstanding pain, fatigue and concomitant symptoms can lead to a number of sick leave spells and longer absences, and resulting in a higher frequency of disability pension for these women.
- Pain, fatigue, decreased muscle endurance and other concomitant symptoms influence the women's lives during most of their waking hours. Working women reported interference from symptoms during 11 hours per day, and non-working women, 16 ½ hours per day.
- Most of the job loss in young newly-diagnosed women was associated with fibromyalgia symptoms.
 - The time structure is interrupted for the women, activities take longer to perform, and the ability to perform valued roles diminishes. Non-working women used significantly more time in caring for others, rest and time of their own.

- It is necessary to encourage these women to find alternative ways of performing tasks and to focus on strategies to control pain and fatigue. Further, more attention needs to be focused on managing stress associated with the psychological demands of family work and the ability to control the pace of these activities.

- Treatment at primary care level needs to be emphasised. Greater knowledge of new findings concerning about fibromyalgia needs to be disseminated in primary care to give women an opportunity to receive an early explanation of their pain, to be believed in, and to be able to start the reorientation process. Rehabilitation groups should start early, preferably in primary care. Individuals subjective experience of their situation is of importance in identifying which factors influence their ability to work and their ability to remain in or return to a work role. Thus, instruments are needed that assess women's total life situation. However, these may need to be complemented with interviews to capture the sometimes invisible occupational demands.

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8. SJUKSKRIVNING ELLER ANNAN FRÅNVARO

1 Sjukskriven sedan _____

(år, månad)

Sjukskrivningsgraden under de sista 3 månaderna:

25% 50% 75% 100% har under perioden varierat mellan _____ - _____

2 Sjukbidrag/förtidspension sedan _____

(år, månad)

Sjukbidrag/förtidspensionens omfattning: 1/4 1/2 2/3 3/4 hel

3 Barnledig sedan _____

(år, månad)

4 Arbetsökande/arbetslös sedan _____

(år, månad)

5 Ålderspensionär

9. Hur många timmar per dag lägger Du vanligen ner på arbete i hemmet?

- mindre än 1 timma per dag
 mer än 1, men mindre än 3 timmar per dag
 3 - 5 timmar per dag
 mer än 5 timmar per dag

NUVARANDE BESVÄR

10. Har Du fortfarande muskelsmärta? 1 Nej (gå till fråga 27)

2 Ja

11. Har Du fått någon ytterligare diagnos? 1 Nej

2 Ja (Ange nedan vilken/vilka):

12a. Hur länge har Du haft muskelsmärta? _____

(år, månad)

12b. När fick Du diagnosen fibromyalgi? _____

(år, månad)

13 Har Du haft några smärtfria perioder under den gångna veckan?

- 1 Nej, har haft smärta ständigt under senaste veckan
- 2 Ja, har varit smärtfri någon gång under senaste veckan
- 3 Ja, har varit smärtfri någon stund varje dag
- 4 Ja, har varit smärtfri några timmar varje dag

14. Om Du haft ständig smärta under senaste veckan har Du haft några smärtfria dagar under de sista 6 månaderna?

- 1 Nej
- 2 Ja

15. Växlar Din smärta i svårighetsgrad?

Här kan Du fylla i ett eller flera alternativ!

- 1 Nej, mycket små eller inga växlingar i smärtan
- 2 Ja, olika mycket olika årstider
- 3 Ja, från vecka till vecka
- 4 Ja, från dag till dag
- 5 Ja, under dagen, t ex olika på morgon och kväll

16 Hur svår är Din smärta?

Försök att ange hur svår Din smärta som regel är en vanlig dag. Endast ett alternativ!

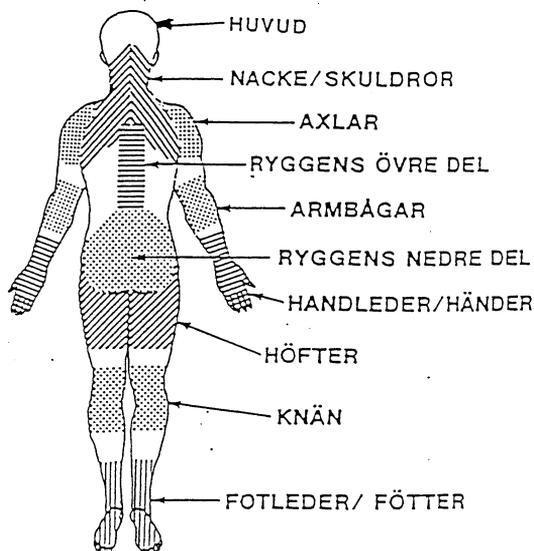
- 1= viss smärta som jag kan bortse från
- 2= viss smärta som jag inte kan bortse från, men som inte hindrar vardagsaktiviteter
- 3 = smärta som försvårar koncentration på vissa sysslor och aktiviteter
- 4 = smärta som försvårar alla sysslor och aktiviteter.
- 5 = smärta som innebär att jag håller mig i stillhet som genom att sitta ner eller gå och lägga sig.

Var finns Din muskelsmärta?

Tänk på var Din muskelsmärta har funnits **under den senaste veckan**. Besvara frågorna genom att sätta kryss i den ruta/ de rutor som stämmer bäst för Dig.

De olika kroppsdelar som avses finns markerade på figuren nederst på denna sida.

	Nej	Ja
	1	2
17. Huvudvärk	<input type="checkbox"/>	<input type="checkbox"/>
18. Nacke, skuldror eller axlar	<input type="checkbox"/>	<input type="checkbox"/>
19. En eller båda armbågarna	<input type="checkbox"/>	<input type="checkbox"/>
20. En eller båda armarna	<input type="checkbox"/>	<input type="checkbox"/>
21. Händer eller handleder	<input type="checkbox"/>	<input type="checkbox"/>
22. Ryggens övre del (bröstryggen)	<input type="checkbox"/>	<input type="checkbox"/>
23. Ryggens nedre del (ländryggen)	<input type="checkbox"/>	<input type="checkbox"/>
24. En eller båda höfterna	<input type="checkbox"/>	<input type="checkbox"/>
25. Ett eller båda knäna	<input type="checkbox"/>	<input type="checkbox"/>
26. Fötter eller fotleder	<input type="checkbox"/>	<input type="checkbox"/>
Smärta på annat område? (ange var) _____		



ANDRA SYMPTOM:

	Nej, nästan aldrig	Nej, sällan	Ja, ibland	Ja, ofta
	1	2	3	4
27. Störs Din sömn av smärta eller värk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Sover Du oroligt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Känner Du Dig utvilad när Du vaknar på morgonen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Känner Du onormal trötthet under dagen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Känner Du Dig okoncentrerad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Känner Du Dig rastlös eller spänd?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Känner Du Dig irriterad eller otålig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Känner Du Dig ängslig, orolig eller nervös?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Känner Du Dig nedstämd, olustig eller ledsen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Besväras Du av "orolig mage"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Har Du omväxlande diarré och förstoppning, krampkänsla i magen, eller "buller och körningar"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Besväras Du av täta tömningar av urinblåsan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Besväras Du av hjärtklappning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Är Du känslig för temperaturförändringar tex mellan inomhus och utomhus?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Besväras Du av muskelstelhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Får Du ökad smärta efter muskelansträngning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Andra problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(ange eventuella ytterligare symptom/ problem): _____

Nedanstående frågor (44-74) besvaras endast av Dig som fortfarande yrkesarbetar, eller är tillfälligt sjukskriven! Om Du inte längre yrkesarbetar gå till fråga 75, sid 9.

NUVARANDE ARBETE

44. Vilket är Ditt nuvarande yrke/ arbete? _____

Beskriv kortfattat Dina arbetsuppgifter _____

45. Hur länge har Du arbetat på Din nuvarande arbetsplats?

Sedan (ange år och ev månad): _____

46. Hur länge har Du arbetat med Dina nuvarande arbetsuppgifter?

Sedan (ange år och ev månad): _____

47. Hur kroppsligt ansträngande är Ditt nuvarande arbete?

Försök att klassa Ditt dagliga arbete efter ett av nedanstående alternativ. De arbeten som är upptagna i nedanstående grupper är bara exempel. Sätt kryss i den ruta som **bäst** beskriver Ditt arbete.

- Grupp 1. Du har övervägande stillasittande arbete och går inte mycket under arbetstid. Exempel på sådana arbeten är skrivbordsarbete och montering av lättare delar.
- Grupp 2. Du har ett arbete där Du går ganska mycket, men inte bär eller lyfter tunga saker. Exempel på sådana arbeten är expeditjonsarbeten, lätt industriarbete, affärsbiträde och viss typ av undervisning där man går mycket.
- Grupp 3. Du går mycket och lyfter dessutom ganska mycket eller går mycket uppför trappor och backar. Exempel är brevbärare, arbete vid tyngre industri, byggnadsarbete och tyngre restaurangarbete.
- Grupp 4. Du har ett tungt kroppsarbete, lyfter tunga föremål och anstränger Dig mycket kroppsligt. Exempel är vådarbeten med tunga lyft och tyngre städarbete.
- Grupp 5. Om inget av ovanstående stämmer med Ditt arbete: Beskriv själv kortfattat: _____

Sätt ett kryss för det alternativ som bäst beskriver kraven i Ditt arbete!

	Nej, nästan aldrig	Nej, sällan	Ja, ibland	Ja, ofta
	1	2	3	4
48. Ställer Ditt arbete stora krav på uppmärksamhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Ställer Ditt arbete stora krav på noggrannhet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Ställer Ditt arbete stora krav på koncentration?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Arbetar Du med små detaljer med stora krav på exakthet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Kräver Ditt arbete att Du arbetar mycket fort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Kräver Ditt arbete att Du arbetar mycket hårt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. Kräver Ditt arbete för stor arbetsinsats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. Har Du tillräckligt med tid för att hinna med arbetsuppgifterna	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. Förekommer det ofta motstridiga krav i Ditt arbete?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. Får Du lära Dig nya saker i Ditt arbete?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. Kräver Ditt arbete skicklighet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. Kräver Ditt arbete påhittighet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Innebär Ditt arbete att man gör samma sak om och om igen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. Har Du frihet att bestämma <i>hur</i> Ditt arbete skall utföras?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Har Du frihet att bestämma <i>vad</i> som skall utföras i Ditt arbete?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Det är en lugn och behaglig stämning på min arbetsplats?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Det är god sammanhållning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. Mina arbetskamrater ställer upp för mig.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Man har förståelse för att jag kan ha en dålig dag.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Jag kommer bra överens med mina överordnade.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. Jag trivs bra med mina arbetskamrater.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

69. Har Din arbetsförmåga påverkats av Din fibromyalgi?

- 1 Nej, (gå till fråga 71)
2 Ja

Om Du svarat Ja, beskriv kortfattat hur Din arbetsförmåga förändrats: _____

70. Vilket symptom hindrar Dig mest? (Ange endast ett alternativ!)

- 1 Smärta
2 Trötthet
3 Annat (beskriv) _____

71. Finns det några arbetsmoment som ökar Dina symptom (smärta, trötthet mm)?

- 1 Nej, (gå till nästa fråga)
2 Ja

Om Du svarat Ja, beskriv vad som ger mer besvär! _____

72. Finns det arbetsmoment som Du har svårt att utföra på grund av Dina besvär?

- 1 Nej
2 Ja (ange exempel) _____
-
-

73. Har några förändringar genomförts i Din arbetssituation på grund av Din fibromyalgi?

- 1 Ja, jag har bytt yrke/ arbetsplats
2 Ja, jag har fått ändrade arbetsuppgifter
3 Ja, jag har fått ändrade arbetstider
4 Ja, arbetsplatsen har anpassats t ex utformats på lämpligare sätt
5 Ja, jag har fått underlättande utrustning t ex hjälpmedel
6 Nej, inga förändringar har gjorts

74. Hur ser Du på Dina möjligheter att fortsätta arbeta på denna arbetsplats?

- 1 Jag räknar med att kunna fortsätta med det arbete jag har under de närmaste åren.
- 2 Jag räknar med att ändra min arbetssituation ganska snart. Ange på vilket sätt Du vill ändra den och varför: _____

Nedanstående frågor (75-77) besvaras endast av Dig som inte längre yrkesarbetar. Om Du yrkesarbetar gå till fråga 78.

OM DU INTE YRKESARBETAR NU

75. Har Du yrkesarbetat tidigare? 1 Nej 2 Ja

Om Ja, vad var orsaken till att Du slutade Ditt yrkesarbete

- 1 Slutade på grund av orsaker som **ej** var relaterade till mitt hälsotillstånd
- 2 Slutade på grund av hälsoskäl som **ej** var relaterad till fibromyalgi
- 2 Slutade på grund av fibromyalgisymptom. Vilka faktorer var mest avgörande för att för att Du slutade Ditt yrkesarbete? _____

76. Gjordes några försök till omplacering eller förändring av arbetsuppgifter eller arbetstid i syfte att möjliggöra fortsatt arbete?

- 1 Nej 2 Ja

Om Ja, beskriv de förändringar som gjordes _____

77. Hade Du kunnat fortsätta arbeta om det funnits ett lämpligare arbete?

- 1 Nej 2 Ja

Kommentar: _____

NUVARANDE SITUATION

Denna fråga besvaras *med hänsyn till Din nuvarande situation* dvs hur nöjd är Du med att inte arbeta eller med att arbeta.

78. **Med hänsyn till Din hälsotillstånd, hur nöjd är Du med Din nuvarande arbetssituation?** (ringa in den siffra som bäst motsvarar Din uppfattning)

Inte alls nöjd	1	2	3	4	5	6	Nöjd i 7 mycket hög grad
----------------------	---	---	---	---	---	---	-----------------------------------

Har Du ytterligare synpunkter som Du vill ge oss som gäller Din arbetssituation eller Din arbetsförmåga? _____

79. **Med hänsyn till Din hälsotillstånd, hur nöjd är Du med Din totala nuvarande livssituation?** (ringa in den siffra som bäst motsvarar Din uppfattning)

Inte alls nöjd	1	2	3	4	5	6	Nöjd i 7 mycket hög grad
----------------------	---	---	---	---	---	---	-----------------------------------

Något Du vill tillägga? _____

Har Du något ytterligare som Du vill berätta om Ditt arbete?

Tack för Din medverkan!

Kan vi få ringa Dig om något är oklart?

- Ja Mitt telefonnummer är...../.....
- Nej