

# **Fibromyalgia and self-regulatory patterns**

Development, maintenance or  
recovery in women

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## **ABSTRACT**

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**Aims:** The overall aim of this thesis was to elucidate psychological processes and development, maintenance or recovery related to fibromyalgia based on in depth interviews. In a next step women with fibromyalgia, women without long-lasting pain and women with long-lasting pain were compared using psychometric instruments selected or developed based on qualitative results. **Methods:** Twenty-one women with fibromyalgia and 8 women recovered were interviewed. Their narrations were analysed using Grounded Theory. Tentative theory was built. The I Myself Scale (IMS) was constructed to mirror self-regulation prior to onset of symptoms and complemented with an instrument on current self-regulation: Structural Analysis of Social Behaviour (SASB) and SF-36 mirroring health related quality of life, regarding the two pain groups. The groups were compared using analysis of variance, principal components analysis paired with discriminant analysis and profile analysis. **Results:** Analyses of the interviews resulted in core concepts of an “unprotected self” (current fibromyalgia) or a “strong but not enough to be weak” self (recovery). Data patterns indicated that the women as children were unprotected in relation to stimuli and affects. Relationships with the parents were characterised by strain and low levels of support. The recovery group had as children simultaneously been able to develop obvious competence and capability to receive help. Psychological vulnerability was in adult life compensated for through pronounced helpfulness and dissociation/repression including intense activity. An increase in mental load such as localised pain or psychosocial crisis preceded onset of fibromyalgia accompanied by impaired cognitive functioning. The state of fibromyalgia meant maintained high levels of mental load such as difficulties of the self-structures, impaired cognitive functioning and somatic symptoms. The recovery group experienced substantial social support and often used mastering strategies to ease symptoms. A decrease in strain as improved life conditions and cease of overexertion preceded recovery. Health was thereafter maintained through careful management as seeking low levels of strain and pacing of activity. Recovery ‘on parole’ also meant personal growth and use of efficacious defences. Psychometrical testing confirmed qualitative data patterns of self-regulation connected to fibromyalgia. Impaired self-reference/understanding of health needs and others not being asked for help and advice was reported before onset of symptoms. Dissociation or repression including intense activity and self-loading were also employed. SASB and SF-36 indicated that women with fibromyalgia experienced higher levels of mental “load” than the other pain group. **Conclusion:** Qualitative data indicated that life prior to onset of fibromyalgia and current fibromyalgia held qualities of impaired self-regulation in relation to mental and physical load. The state of recovery relied on improved self-regulation allowed by conditions of life. Quantitative data patterns confirmed qualitative results on impaired self-protection before onset of fibromyalgia and a specifically high level of mental load during the state of fibromyalgia. Psychological disregulation is discussed and hypothesised to cause but also later in the process parallel alterations in somatic homeostatic functions. Recovery could mean that biological regulation regarding strain is replaced with more of “psycho-social” regulation as careful pacing of work. Implications for treatment are suggested.

**Key words:** qualitative data, interviews, psychometric instruments, dissociation, repression, activity, self-loading, self-regulation, recovery

## **Fibromyalgia and self-regulatory patterns. Development, maintenance or recovery in women.**

### **Background**

Fibromyalgia is a chronic pain syndrome without any established aetiology and the classification and diagnosis are based on certain criteria. The criteria most widely accepted are those proposed by The American College of Rheumatology (ACR). These criteria include a history of widespread pain in all four quadrants of the body, lasting for three months or more, and pain elicited by digital palpation of, at least, 11 out of 18 specified bilateral tender points (Wolfe et al., 1990).

### *Prevalence*

The prevalence of fibromyalgia is from a random sample in the United States estimated to 2% of the population (Wolfe, Ross, Andersen, Russel & Herbert, 1995). Fibromyalgia is simultaneously found to be common in countries worldwide, including so called developing countries. The prevalence in South Africa was by Kwiatek, Barnden and Tedman (2000) estimated to 3.2%. The corresponding figure regarding Pakistan was estimated to 2.1 % (Farooqi & Gibson, 1998). Prevalence in Poland was estimated to 4.5% by Gaglieze and Katz (2000) and in Finland 0.8% by Mäkelä and Heliövaara (1991). From Swedish explorations on prevalence of fibromyalgia in the general population, the prevalence was estimated to 1% (Lindell, Bergman, Petersson, Jacobsson & Herrstrom, 2000) or to 1.3 % (Jacobsson, Lindgarde & Manthorpe, 1989).

Women are seven times more likely to fulfil the diagnostic criteria of fibromyalgia than men and the prevalence of the syndrome increases with age (Wolfe, Ross, Andersen, Russel & Herbert, 1995). Prevalence in women is by Rush and Ameis (1995) reported to show a peak of 10% in the age group of 55-64 years, then steadily declining. After 60 years of age the prevalence is estimated to approximately 7% in women (Wolfe, Ross, Andersen, Russel & Herbert, 1995). The decline in prevalence rates of fibromyalgia, being regarded a non lethal disease, might be explained by mortality due to co morbidity with other diseases (as rheumatoid arthritis) with a mortality rate greater than one (White & Hart, 2001). The co morbidity with rheumatoid arthritis is estimated to 32% (Romano, 1992), systemic lupus erythematosus (SLE) 59% (Romano, 1992) and osteoarthritis 51% (Romano, 1992). Besides these groups and the female part of the population, other groups have also been reported in connection to increased prevalence of fibromyalgia. Simms et al. (1992) reported that fibromyalgia syndrome was found in 41% of HIV-infected patients with musculoskeletal symptoms and in approximately 11% of all

HIV-infected patients most often with a background of intravenous drug use. Increased rates were also found in patients with post traumatic stress disorder (PTSD) (Amir et al., 1997) and Gulf War veterans (The Iowa Persian Gulf Study Group, 1997).

#### *The course of the symptoms*

The course of the fibromyalgia syndrome is by Felson and Goldenberg (1986) regarded as chronic with few generally transitory remissions. A more positive prognosis is described for children (Buskila et al., 1995) and for sufferers with slighter symptoms (Granges, Zilko & Littlejohn, 1993). Cronan, Serber, Walen and Jaffe (2002) reported that older individuals (age 60-85 years) exhibited decrease in symptomatology, simultaneously as duration of the disease was longer than that of patients in younger age groups. Notably a majority of the assessed participants were well educated and belonged to a health maintenance organisation in the United States. Ledingham, Doherty and Doherty (1993) reported full remission of symptoms in 3 % of adult patients in a 4-year follow up study and Bengtsson, Bäckman, Lindblom and Skogh (1994) of 2% of adult patients 8 years after diagnosis. The duration and frequency of the fibromyalgia syndrome might well explain that 2-5% of the consultations with a general practitioner or 20% with a rheumatologist are due to fibromyalgia (Goldenberg, 1993).

#### *Clusters and levels of complaints*

The main symptom in patients with fibromyalgia is pain, in particular muscular pain. Other somatic symptoms than pain are also common in relation to the syndrome. Patients with fibromyalgia report significantly more irritable bowel syndrome, migraine headaches and severe menstrual pain than other subjects with chronic pain or healthy controls (Poyhia, Da Costa & Fitzcharles, 2001). Fatigue and vertigo are also common in relation to fibromyalgia (Waylonis & Heck, 1992). Many patients with fibromyalgia claim that fatigue is more troublesome than the pain itself. From interviews with women suffering from fibromyalgia, the fatigue was described as a sense of almost constant sleepiness or feeling of being screened off (Söderberg, 1999). The condition of fibromyalgia influences daily life to a great extent. Patients with fibromyalgia describe more intense feelings of illness than do patients with rheumatoid arthritis (RA) (Bengtsson et al., 1986). They also report cognitive difficulties and in comparison to another group of pain-patients (RA-patients), fibromyalgia patients show higher impact in the psychosocial dimension at the same time as the impact in the physical dimension is lower (Henriksson, 1995).

The pain and fatigue of fibromyalgia are described as constituting a major obstacle in fulfilling the tasks of most women, in their active periods in life. Thereby, the difficulties stemming from pain and fatigue are depicted as becoming additional stressors, causing further increase in pain (Henriksson, 1995). Seventy percent of patients with fibromyalgia are reported to have noted that their symptoms were aggravated by noise, light, stress, posture and different kinds of weather (Waylonis & Heck, 1992). White, Nielson, Harth, Ostbye and Speechley (2002) found that patients being supplied with the diagnosis/label of fibromyalgia did not exhibit adverse effect on clinical outcome after 3 years. Rather a subjectively improved satisfaction with health was shown, by the researchers commented in terms of improvement in medical management as pacing of activity. Scott (1999) documented that patients with fibromyalgia that found themselves “having been taken seriously” by health care showed a lower degree of symptoms when compared to other patients with fibromyalgia. A parallel to this finding is reported by Felson and Goldenberg (1986) relating that a number of patients with fibromyalgia, when given the opportunity to freely comment on their disease, assigned a major role of life events in the exacerbation or alleviation of symptoms.

#### *Biomedical research*

Biomedical research has so far failed to prove any significant morphological changes in the muscle tissue in fibromyalgia. Increased muscle tone, evidenced by inability of patients with fibromyalgia to relax between muscular contractions was found, while maximal muscle strength and endurance did not differ between patients and controls (Elert, Rantapää-Dahlqvist, Henriksson-Larsén, Lorentzon & Gerdle, 1992). Bäckman, Bengtsson, Bengtsson, Lennmarken and Henriksson (1988) also found a lower muscle relaxation rate in patients with fibromyalgia. The rate of relaxation was increased in the patients during sympathetic blockade. Van Denderen, Boersma, Zeinstra, Hollander and van Neerbos (1992) reported decreased response of the sympathetic nervous system to exercise in patients with fibromyalgia when compared to healthy controls. From a study of young men with symptoms of fibromyalgia, Visuri, Lindholm, Lindqvist, Dahlstrom and Viljanen (1992) related indications of both a decreased level of activity of the sympathetic nervous system and an increase in sympathetic nervous reactivity of the cardiovascular system. Griep, Boersma and de Kloet (1993) suggested that fibromyalgia is related to a documented neuroendocrine dysregulation characterized by, for example, relative hypocortisolemia. This hypothalamic-pituitary-adrenal (HPA) response pattern was contrasted with the hypercortisolemic responses observed in

patients with depression by the researchers (Griep, Boersma & de Kloet, 1993).

Patients with fibromyalgia suffer from impaired sleep characterized by reduced sleep efficiency. Electro-encephalogram (EEG) shows a disordered sleep physiology in the form of a reduced amount of slow wave sleep and an abnormal alpha wave intrusion in non rapid eye movement (NREM-sleep) termed alpha-delta sleep (Moldofsky, Scarisbrick, England & Smythe, 1975). The alpha EEG sleep anomaly, according to Anch, Lue, McLean and Moldofsky (1991), may reflect a vigilant arousal state during nocturnal sleep and result, besides the daytime experience of unrefreshing sleep, also in psychological distress. The sleep-physiology of female fibromyalgia patients was compared to the sleep-physiology of female patients with post accident pain by Saskin, Moldofsky and Lue (1986). Post accident pain was defined as complaints of musculoskeletal pain, fatigue and nonrestorative sleep following a non-physical injurious motor vehicle or work-related accident. The pattern of NREM sleep anomaly showed to be the same. This was, on behalf of the post accident group, interpreted in terms of emotional stress of the accident and a subsequent posttraumatic pain disorder (Saski, Moldofsky & Lue, 1986). Martinez-Lanvin, Hermosillo, Rosas and Soto (1998) investigated heart rate variability related to fibromyalgia. Patients and controls were studied during 24 hours and in their natural environment performing everyday routines. The researchers found a decrease in parasympathetic influx and an increase in the sympathetic influx on heart rate including an alteration of the circadian variation equivalent to nocturnal sympathetic hyperactivity. The phenomenon of nocturnal hyperactivity is discussed in terms of irritating normal sleep patterns including parasympathetic dominance during deep stages of sleep. Disturbance of deep stages of sleep was also suggested by Martinez-Lanvin et al. (1999) based on an investigation of the relationship between heart rate variability and patterns of sleep in patients with fibromyalgia.

The origin of the pain in fibromyalgia has been widely discussed. A possible cause was illustrated by an experiment of Moldofsky and Scarisbrick (1976), reporting on a sleep deprivation condition of healthy volunteers. One of the groups of participants was deprived of stage 4 NREM sleep and subsequently reported more musculoskeletal symptoms during the deprivation condition than did a group that was deprived of REM sleep. The group deprived of NREM sleep also showed an increase in muscle tenderness. The REM deprived group did not show this change. The researchers discuss the relationship between the symptoms of

fibromyalgia and disturbance of NREM sleep in terms of NREM sleep, unlike REM sleep being involved in restoration of physical functioning. A common opinion is that the pain is of both peripheral and central origin (Bengtsson & Henriksson, 1996), meaning, for example, stemming both from processes in the muscles themselves and from alterations in the central nociceptive system. Bengtsson, Bengtsson and Jorfeldt (1989) suggested fibromyalgia pain to be of peripheral or spinal origin after epidural administration of lignocaine, resulting in tender points completely disappearing. Another hypothesised cause of the fibromyalgia pain is crisis of energy of the muscle fibres together with impairment of inhibition, on a central level of the nervous system in relation to pain impulses of a peripheral origin (Bengtsson & Henriksson, 1996). Martinez-Lavin (2002) suggested that sympathetic nervous system dysfunction is frequent in patients with fibromyalgia. The related dysfunction is characterised by both hyperactivity and hyporeactivity to stress. Relentless sympathetic hyperactivity is suggested to explain generalised pain and tenderness at palpation of specified points through the mechanism of “sympathetically maintained” pain documented by Martinez-Lavin (2001).

#### *Psychosocial stress*

One line of investigation has been of traumatic experiences or levels of lifetime stress. Amir et al. (1997) found that 21% of a sample of posttraumatic stress disorder (PTSD) patients fulfilled the criteria for fibromyalgia. The patients suffering from fibromyalgia were in worse shape psychologically than those not suffering from fibromyalgia. In this report the authors raised the question on PTSD prevalence in patients with fibromyalgia. Cohen et al. (2002) also found that the incidence of PTSD was 57% in a sample consisting of equal amounts of men and women with fibromyalgia and Sherman, Turk and Okifuji (2000) reported that the symptoms of PTSD were prevalent in 56% of fibromyalgia patients. At the same time no statistically significant difference was found between patients with or without PTSD symptoms, regarding the rate of onset of fibromyalgia coinciding with accident or injury (Sherman, Turk & Okifuji, 2000). A lifetime prevalence rate of 7-12 % of PTSD in the general population is reported by Seedat and Stein (2001).

Patients with fibromyalgia have by Poyhia, Da Costa and Fitzcharles (2001) been found to report more adverse experiences throughout life in the form of physical and psychological trauma than other subjects with chronic pain. According to Walker et al. (1997), patients with fibromyalgia show, compared with other patients with pain, significantly higher lifetime prevalence rates of all forms of victimisation, both adult

and childhood, as well as combinations of adult and childhood trauma. Experiences of physical assault in adulthood showed a strong relationship with fibromyalgia. Van Houdenhove et al. (2001) reported that patients with fibromyalgia showed a significantly high prevalence of emotional neglect and a considerable subgroup of them had experienced lifelong victimisation. The perpetrators were most frequently found in the families. When compared to other pain patients, fibromyalgia has further been associated with the experience of high levels of daily stress (Dailey, Bishop, Russell & Fletcher, 1990; Uveges et al, 1990).

### *Research in the psychological dimension*

Research in the psychological dimension has so far mainly been carried out by means of quantitative measures and general-purpose instruments. Through comparisons of different groups of patients with pain using the Minnesota Multiphasic Personality Inventory (MMPI), differences between the fibromyalgia group and other groups of patients that are forced to handle long-lasting pain have been shown (Payne et al., 1982; Wolfe et al., 1984; Ahles, Yunus, Gaulier, Riley & Masi 1985; Ellertsen, Vaerøy, Endresen & Förre, 1990). The test-profiles indicate that the fibromyalgia-group suffers from somewhat higher frequencies of psychological difficulties than the other groups. Hallberg and Carlsson (1998) described higher levels of trait anxiety in patients with fibromyalgia when compared to patients with work-related pain. The level of measured state anxiety did not differ significantly between the groups. Similar results have been reported by Ekselius, Bengtsson and von Knorring (1998). When compared to healthy controls, fibromyalgia-patients show, as indicated by the Karolinska Scale of Personality (KSP), higher levels of somatic anxiety but lower levels of psychic anxiety. Somatic anxiety is described in terms of, for example, palpitation of the heart, sweating and shortness of breath.

Subgroups of patients with fibromyalgia have been identified. Johnson (1997) identified subgroups regarding sense of self-esteem. Subgroups in the dimension of suffering and not suffering from symptoms of post traumatic stress disorder (PTSD) were shown by Cohen et al. (2002) and Sherman, Turk and Okifuji (2000) and in the dimension of being depressed/not being depressed by Landrö and Winnem (1987), Ellertsen, Vaerøy, Endresen and Förre (1990) and Johnson (1997).

Brosscot and Aarsse (2001) investigated the ability to process emotions in a group of patients with fibromyalgia when compared to healthy controls. Their hypothesis was that experiences of anxiety were restricted in the fibromyalgia group due to avoidance marked by a pronounced attitude of



‘social desirability’. Contrary to their expectations, their finding was that fibromyalgia was connected with ‘a relatively uncommon combination’ of both high levels of ‘social desirability’-defence measures and high levels of trait anxiety plus higher levels of negative affect at the same time. When compared to controls, the fibromyalgia group also scored higher on the Toronto Alexithymia Scale (TAS) (Brosschot and Aarsse, 2001). Toskala, Kangasniemi, Vasarinen and Nurmikko (1993) combined qualitative and quantitative methods when showing decreased ability to symbolise destructive affects on behalf of fibromyalgia patients. Jacobsson (1989) investigated defensive structures/mechanisms, activated by subliminal threatening stimuli (Defence Mechanism Test modified (DMTm)- technique), in patients with fibromyalgia and made comparisons with other groups of pain patients. Patterns of suppression of the self-representation combined with denial in relation to loss emerged in the fibromyalgia group. Repression of the self-representation could, based on the theoretical framework of DMTm (Andersson & Hallborg, 1986), be regarded as protective measures in relation to fear of being damaged by something “unconditional evil” from within the psychological structure of the individual herself. Based on content analysis of spontaneous speech on a self-selected dramatic or interesting experience, women with fibromyalgia exhibited, when compared to healthy women and women suffering from functional dyspepsia, an increased level of interpreted mutilation anxiety (Malt & Ursin, 2003). The finding was partially discussed in terms of a psychological marker of underlying pain proneness due to neurobiological vulnerability.

In contrast to a group of patients with rheumatoid arthritis patients with fibromyalgia was by Perry et al. (1988) documented to show a self-report-pattern of low or negative correlation between different pain rating scales. These results were interpreted in terms of pain related to fibromyalgia being more complex or different from pain in syndromes with a well-known organic base. Through experimental investigations (psychophysics) another incongruous perceptual pattern was mapped in relation to fibromyalgia (Harju, 2001). A striking phenomenon was that all women in a fibromyalgia group reported cold stimulation (20-10 deg C) as heat, so called ‘paradoxical heat’. The ‘paradoxical heat’ phenomenon was also reported by 5 out of 7 in a group of patients with central post stroke-pain but only present in 6% of healthy controls.

### *Psychometrics and rehabilitation*

Psychometric research has been used also to predict good or bad outcome of rehabilitation measures or programs. Granges, Zilko and Littlejohn (1993) found that regular physical exercise, rather than drug or specific

physical therapies, correlated highly with good outcome. Analysis of mood and coping strategies showed low correlations with fibromyalgia activity. In line with this, Bennet et al. (1996) and Keel, Bodoky, Urs and Müller (1998) found that depression did not predict outcome of rehabilitation. Poorer outcome was instead predicted by coping strategies characterised by catastrophizing, and Minnesota Multiphasic Personality Inventory (MMPI)-scores of psychological disturbance. The so-called pain profiles of the MMPI did not predict outcome. Fitness evaluated at the beginning of a rehabilitation programme did not predict outcome of rehabilitation (Bennet et al., 1996). In a study designed to compare group treatments of relaxation technique with group treatment combining relaxation technique with group therapy, the group receiving both kinds of treatment was found to have the best outcome results. The most successful participants had all participated in the group receiving group therapy and were also singled out as having suffered from pain for a shorter period of time, not having applied for disability pension and showing more initiative for conflict resolutions as measured by projective testing (Keel, Bodoky, Urs & Müller, 1998). In spite of a number of research measures and designs aiming at the characteristics of patients improved by different kinds of therapeutic programmes no study on psychological functioning has so far been designed or conducted for the investigation of the characteristics and conditions of individuals having been diagnosed with fibromyalgia but presently being recovered.

### *Qualitative attempts*

Theory-generating qualitative attempts in the domain of psychosocial processes involved in developing, maintaining or recovering from fibromyalgia are so far few in numbers. Altered psychological functioning in connection to the syndrome is, at the same time, documented by way of other scientific approaches as cognitive difficulties (Henriksson, 1995; Sletvold, Stiles & Landrö, 1994; Grace, Nielson, Hopkins & Berg, 1999), vulnerability to stress (Waylonis & Heck, 1992), experiences of higher levels of daily stress when compared to other patients with pain (Dailey, Bishop, Russell & Fletcher, 1990; Uveges et al., 1990), fatigue (Söderberg, 1999; Waylonis & Heck, 1992) or high levels of impact in the psychosocial dimension (Henriksson, 1995). Hallberg and Carlsson (1998) though, used grounded theory and described women presently suffering from fibromyalgia 'as they themselves tell it'. The women were found to be traumatised in the psychosocial dimension, over-active and preoccupied by their pain. The maintenance of the pain-condition was partly interpreted as caused by secondary gains or reinforced by medical doctors regarding the sick-role.

The analysis of psychological functioning and psychological processes related to the course of fibromyalgia, in line with clinical psychological methodology, such as structural interviews, has so far scarcely begun. Concepts for descriptions of psychological functioning and interactions between psychological functioning, conditions of life and symptoms-variability have not been formulated or grounded in sufficient amount of data - expressions of lived experiences. The identification and conceptualisation of emotional age, maturational levels of object-relations, structure of defence, alexithymic difficulties or psychosomatic mechanisms still remains an unsolved task. Such conceptualisations combined with the perspective of processes over the years are still lacking. Psychological research has so far been dominated by quantitative attempts, these attempts also not being grounded in theoretical formulations emanating from naturalistic inquiries. In this thesis an attempt is made to accomplish conceptualisations based on the informants' own words as well as creation, selection and use of inventories based on theoretical formulations based on analysis of interview data.

### **General aim**

The overall aim of the studies was to illuminate psychological patterns and psychological processes related to development and course of fibromyalgia in women, using clinical psychological procedures. Theories or hypotheses generated from qualitative studies were in a final phase to be tested through traditional logico-deductive methodology.

### **Specific aim of study 1**

The specific aim of study 1 was to elucidate psychological functioning and the process of being stricken with fibromyalgia in women.

### **Specific aim of study 2**

The specific aim of study 2 was to elucidate psychological functioning and psychosocial conditions of women originally diagnosed with fibromyalgia but presently not fulfilling the diagnostic criteria and also subjectively being recovered.

### **Specific aim study 3**

The specific aim of study 3 was to describe psychological functioning in women with fibromyalgia based on two psychometrical instruments. First, a hypothesis that the results on a scale, based on interview data on adult psychological functioning prior to development of fibromyalgia (Wentz, Lindberg & Hallberg, 2004), would differ between a group of women suffering from fibromyalgia and an age- and education matched

comparison group was to be tested. The second hypothesis to be tested was that the groups would differ on a subscale of the Structural Analysis of Social Behaviour (SASB) mirroring the current relationship of the individual to “the self”.

#### **Specific aim study 4**

The specific aim of study 4 was to describe psychological functioning, contextualised with health related quality of life, in women with fibromyalgia based on three psychometrical instruments. Two hypotheses concerned differences between a group of women suffering from fibromyalgia and an age- and education matched comparison group with organically explained long-lasting pain on the same two instruments as in study 3. Furthermore, the result from the psychometric scales was to be related to the result from measurements of health related quality of life.

### **Method**

#### *Participants*

##### *Study 1 and study 2*

In study 1 the sample consisted of 21 women aged 26-72 years (mean 51 years). The women fulfilled the ACR diagnostic criteria of fibromyalgia (Wolfe, et al., 1990). The sample was selected strategically in order to get as much variation as possible according to age, education, profession, sick-leave or working, early retirement and remission and relapse of symptoms. The educational background of the women ranged between 6-17 years of schooling. Duration of generalised pain ranged from 1,5 to 26 years. Sixteen women were married or lived with a partner. Three women lived alone after being divorced. Two women were widowed. In study 2 the sample consisted of 8 women aged 39-68 years (mean 56 years). Five women were married or lived with a partner. Two were divorced and one was widowed. The women’s educational background ranged between 8 and 19 years (mean 13,7 years). The sample was not chosen strategically, due to the small amount of individuals having recovered from fibromyalgia. The participants had a medical record of fibromyalgia but they did not presently fulfil the ACR diagnostic criteria (Wolfe, et al., 1990). The women participating in study 2 were both objectively and subjectively recovered since they also considered themselves as having recovered from the syndrome of fibromyalgia.

##### *Study 3 and 4.*

The participants of study 3 and 4 were recruited through an advert in a morning paper asking for women suffering from fibromyalgia that

wanted to contribute to better understanding of psychological aspects of long-lasting pain. An incitement put forward in the advert was to improve the skills of Public Health Care to meet the needs of the individual suffering from fibromyalgia. To study 3 a comparison group of 30 women not suffering from long-lasting pain was recruited through query on workplaces or social [settings] knowledgeable to the research group. Thirty-five “pain free” women were consecutively recruited. Out of these, 30 women were included in the control group in order to achieve an as close match as possible regarding age and educational level. The participants in the fibromyalgia-group had a median age of 52 years. The median age of the women in the control group was 53 years. To study 4 a comparison group of 23 women suffering from long-lasting pain were recruited. The group consisted of age matched women queuing up for surgery in relation to arthrosis of the hip or the knees and women that were consecutive patients diagnosed with rheumatoid arthritis of an out patient Rheumatology clinic. The median age of the women in the comparison group was 58 years. The duration of pain in the fibromyalgia group ranged from 1 to 50 years, mean 15.4(SD 12.1) years and in the comparison group with long lasting pain from 3 to 54 years, mean 13.02 (SD 10.53).

### *Procedure*

#### *Study 1 and 2*

The participants of study 1 were recruited from primary care, a private rheumatologist’s out patient clinic and hospital specialist units, all in the Gothenburg region. The women were approached by their regular medical doctor receiving a letter informing about the study. In study 2 the participants were recruited by advertisement in a morning paper asking for women who had recovered from fibromyalgia. The future participants of study 2 were asked to call the author (KW) at the Pain Clinic at Sahlgrenska University Hospital/Mölndal. They were then sent a letter informing about the study. Some women responding to the advertisement had had the experience of being diagnosed with fibromyalgia and thereafter experiencing the remission of symptoms. In a third phase they got their symptoms back. Since data patterns of study 1 pointed in the direction of a more positive development in some cases these women were sampled into study 1. In relation to both studies the women were asked to mail their consent in writing if interested in participating. After informed consent the participants underwent medical examination by the medical doctor of the research group. In the case of study 1, the aim of medical examination was to confirm the diagnoses of fibromyalgia. In the case of study 2, the participants had to give their consent in writing to

obtain their medical records from the occasion of fulfilling the ACR criteria of fibromyalgia. The medical record was ordered and checked by the medical doctor of the research group. The aim of the medical examination in study 2 was to confirm their presently not fulfilling the ACR criteria of fibromyalgia. The women were interviewed at the Pain Clinic, Sahlgrenska University Hospital/Möln dal. These interviews were semi-structured, in depth, and lasted 1 to 2 hours. They focused on the onset of symptoms, course of the illness, variation in symptoms, life-style, activity style, life history, object relations, wishes regarding rehabilitation and views regarding reasons behind the development of fibromyalgia symptoms. The interview guide was adjusted alongside data gathering, in order to further illuminate data patterns that emerged out of the interviews. The participants of study 2 were also asked about the process of remission of symptoms. The interviews were tape recorded, transcribed verbatim and consecutively analysed according to grounded theory. The women were interviewed by (KW), a clinical psychologist with experience from psychiatry and pain rehabilitation.

#### *Study 3 and 4*

The group of women diagnosed with fibromyalgia participating in study 3 and 4 was composed out of the first 200 women answering the call for participants. After a short informative phone call the women were sent a letter informing about the study including a form of written consent that could return by mail to the research group. Presumptive participants were summoned by telephone during daytime to undergo medical examination at Neuromuscular Centre Sahlgrenska University Hospital/Möln dal. Medical examination was performed by a medical doctor specialised in neurology and rehabilitation medicine in order to confirm the ACR criteria (Wolfe, et al., 1990) diagnosis of fibromyalgia. After a confirmed diagnosis the participant was summoned to the author also at the Neuromuscular Centre Sahlgrenska University Hospital/Möln dal in order to fill in the SF-36), the “I myself-scale” and the Structural Analysis of Social Behaviour (SASB). In order to collect a minimum of 30 complete forms the sample of women diagnosed with fibromyalgia had to consist of 36 participants. The participants diagnosed with fibromyalgia while taking the tests, sometimes reported that sections of the forms could not be answered due to not having grown up with their father, their mother etc. Two women who received a diagnosis during medical examination did not participate in the psychological assessment due to reported somatic or psychological problems. To study 3 a comparison group of 30 women not suffering from long-lasting pain was recruited through query on workplaces or social [settings] knowledgeable to the research group. These women were mailed or handed a letter informing about the study.

The letters also contained a form of consent regarding participation that could be returned by mail or handed to the research group.

To study 4 an additional group of 23 women suffering from long-lasting pain was recruited. These participants were recruited both from queuing up for surgery related to osteoarthritis paired with either knee or hip pain at Sahlgrenska University hospital/Möndal and from the out patients Rheumatology clinic Sahlgrenska University hospital/Möndal then diagnosed with rheumatoid arthritis (RA). The women queuing up for surgery were mailed a letter informing about the study and the women suffering from rheumatoid arthritis were handed the same letter of information from their regular medical doctor. The letters besides information of the study contained a form of consent regarding participation that could be returned by mail to the research group. For the convenience of the participants, all participants with long-lasting pain like most “pain-free” controls were sent the surveys by post and were asked to return the completed forms.

### *Instruments*

*The I myself-scale* was developed based on an analysis by KW of interviews with women currently suffering from fibromyalgia (Wentz et al., 2004a). The analysis resulted in identification of specific psychological patterns of functioning -“unprotected self” and “compensating strategies”. Selected dimensions were transferred into a sub-scale containing 89 items. The scale was drafted to mirror qualities of impaired signalling functioning/affect functioning (9 items), psychologically invaded (3 items), impaired autonomy (5 items), impaired self definition (8 items), alloplastic difficulties (10 items), self destructiveness (8 items), motoric self representation (4 items), strength/being in control (10 items), compensating activity (11 items), redirection of perception (4 items), hypomanic repair (5), self-suppression (9) and suppressed thinking (3 items). The forming of the scale aimed at mirroring psychological functioning present before, not resulting from, the onset of generalised pain. The women with fibromyalgia were instructed to think back at their adult life before they were stricken with long-lasting pain. The pain-free control-group was asked to rate their adult life 10-15 years back. If they were presently younger than 35 years old they were asked to think about their life at the age about 25 years. Each item was answered on a 5-point scale ranging from “Does not agree at all” to “Totally agree”.

The SASB (*structural analysis of social behaviour*)-scale is constructed upon interpersonal theory (Benjamin, 1974). Central to this theory is the concept of the self. In the self-report form of SASB the self-image sub-scale consists of 36 items forming eight clusters representing how the individual relates to her/himself. Two clusters represent spontaneity versus self-control. Three clusters represent attachment and three clusters represent disruption. Normal development is characterised by a balance between dependence/independence and establishment of a base-line level in attachment clusters.

The Swedish version of the self-report questionnaire SASB developed by Bodlund and Armelius (1994) contains 36 items/statements to be qualified regarding agreement-disagreement on a scale from 0, 10, and 20 up to 100%. Reliability of the Swedish version of the SASB self-scale is calculated employing different statistical methods, showing a high average reliability of  $r=0.87$ . Content validity of the instrument has been investigated employing factor analysis. A two factor model was extracted confirming the two dimensions of the model (love-hate and spontaneity-control). The clusters of the model in the dimension of the self are named: *accepting self, loving self, nourishing self- blaming self, hating self, ignoring self, spontaneous self* and *controlling self*.

The SASB-scale was chosen to constitute a complement or possible validation of the “I myself-scale” due to both scales dealing with matters of the self as self-care and self-destructiveness. The SASB sub-scale deals with the present time.

In order to be able to compare women with fibromyalgia and women with organically explained long lasting pain (study 4) regarding the results from the psychometric scales, the results needed to be evaluated in the context of current levels of pain, psychological well being and physical functioning. This was mapped using the health related quality of life-instrument Short Form-36 (SF-36) consisting of 8 subscales forming 2 summary indexes. The sub-scales rate on either two-, three-, five- or six-point scales. Physical Function (PF) (10 items, 3-point scale), Role Physical (RP) (4 items, 2-point scale), Body Pain (BP) (2 items, 6-point scale), General Health (GH) (4 items, 5-point scale) are measure of physical health (PH). Vitality (VT) (4 items, 6-point scale), Social Functioning (SF) (2 items, 5-point scale), Role Emotional (RE) (3 items, 2-point scale) and Mental Health (MH) (5 items, 6-point scale) measures of mental health. The PF scale assesses the extent to which participants are limited in their ability to engage in a variety of daily activities. The RF scale assesses ability to perform a job or other regular activities due to



limited physical functioning. The BP scale assesses level of pain and functional limitation due to pain. The GH scale mirrors self-evaluation of health and expectations regarding health for the future. The VT scale measures access to a sense of vitality or energy. The scale measuring social functioning, SF, summarises limitations due to both physical and psychological difficulties. The RE scale assesses ability to perform a job or other regular activities from the angle of psychological difficulties. The MH scale mirrors psychological state or well-being during the last week. From the subscales of SF-36 two summary indexes of Physical Health (PCS) and Mental Health (MCS) are derived. These indexes could be used in order to interpret differences between physical and mental health. Interpretation of the summary indexes should include evaluation of the contributing subscales.

### *Data analyses*

#### *Study 1 and 2*

The interviews were analysed in line with grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1996). The aim of this method is conceptualisation of data-patterns to build a theory (in the sense of a hypothesis) through inductive measures. The inductive process starts with coding of data. In both studies the interviews were coded using both *in vivo* codes meaning conceptualising the content of the interviews, using ‘verbatim abstractions’ stemming from the informants exact words, and combining them with *in vitro* concepts more related to theoretical frameworks. This was a conscious decision aiming at capturing as much as possible of qualities in the dimension of experiences, conditions and psychological functioning present in the interviews. The coding procedures resulted in between 500 and 700 codes in each interview. In this way a thorough scrutiny of the interviews was carried out. In a second step the codes were classified and categories, formed by codes that expressed a similar meaning, were created. Codes like *weeks without good sleep* formed together with other codes with similar content the category of *sleep-deprivation*. Codes like *existential threat* and *vulnerable to stigmatization* were clustered into the category *existential threat*. In a third step the category *existential threat* together with *exhaustion*, *sleep-deprivation* and other categories like *pain* and *conflict*, in the form of subcategories, pertained to the forming of a higher order category *increase in mental load –development of fibromyalgia*. This next step of labelling and creating categories meant more of a phase of theory building.

The process also contained procedures of coding of relationships between emerging categories. Models mirroring each participant were constructed. These ‘single person’-models contained categories, pertaining subcategories and codes and relationships between categories. The models of each participant were compared to each other to discover commonalities and differences in between them. Some of the differences were built into the theory as variation. The model of study 1 focused more on psychological processes related to the ongoing condition of fibromyalgia whereas the model of study 2 also mirrored the psychological process expressed in relation to symptom remission and maintenance of recovery. In study 1, 13 different models were built. The last eight interviews were merely coded and memos of psychological functioning and conditions were taken. Memos and codes were compared to the emerging model (of the group as a whole) and the emerging theory. In study 2, eight different models were built and compared to each other.

Theory was also built through a further step of identifying core concepts of the two emerging models. The other categories were related to the core concepts of each model. From this kind of categorisation a model mirroring data-analysis on a group level was built. In both models a core concept of self-structure related to conditions of life was identified. These concepts were both similar to each other and different. The labels *unprotected self* and *on parole –strengthened enough to be weak* are supposed to mirror this relationship.

Sampling of literature completed the inductive process. For example, the incoherence of psychological functioning resulted in sampling of research articles on background factors of dissociation. Data patterns of childhood conditions of strain and lack of support lead to the studying of child abuse literature and research reports on children living with “traumatic stress disorder”, i.e., living under traumatic circumstances.

#### *Study 3 and 4*

Data analyses followed a five-step process. First a test of the internal consistency by means of Chronbach’s alpha of the “I myself scale” (IMS) was conducted in order to examine whether the scale mirrored an underlying theoretical construct or not. One-way analyses of variance (ANOVA) were performed in order to examine whether the fibromyalgia-group and the comparison groups respectively differed on single items of the “I myself scale”. One-way ANOVAs were also conducted in order to investigate whether there were statistically significant group differences on clusters of items forming the dimensions of the SASB-model, and in study 4 also the indexes of SF-36. In a third step a Partial Least Square

Discriminant Analysis (PLS-DA) (Henningsson, Sundbom, Armelius & Erdberg, 2001) was performed using the 89 items of the “I myself scale” as predictors of group membership. The purpose of this analysis was to discover latent variable structures (principal components) and also to determine degree of contribution of individual x-variables, in explaining group membership (Henningsson, Sundbom, Armelius & Erdberg, 2001). Unlike in Factor Analysis these latent variables were not hypothesised to mirror an underlying factor explaining the correlation among the variables. Instead the non-independence of the variables brings important information about the participants. In PLS-DA type 1 errors can also be avoided since the number of extracted latent variables is small and the number of cases easily sufficiently exceeds this number. Unlike Principal Component Analysis not only the relationship between the x-variables and the individual cases was calculated but also the ability of the model to predict group membership. Group membership was represented by the creation of two dummy variables (Y) respectively. The Principal Components were calculated based on a covariance matrix, then using the method of least squares to reduce variables into components. Further in the process, the x variables were weighed or attached with loadings in order to achieve a maximisation of correlation between the original x-scores of the individuals and their observed belonging to a group (dummy variable Y). A variable importance score (VIP) of the all x-variables was also computed in order to compare all the x-variables according to relevance in explaining Y or group membership. The variables with weights and VIP-values meaning high relevance for defining each group were listed group wise.

In a further step of analysis the score profiles of the two or three groups were examined. Consequently, 42 of the 89 items of the “I myself scale” were rescaled or inverted so that the higher the reported score of each of the 89 items, the higher the reported potential or endured mental or physical load. All the items of the IMS including the items rescaled “in direction of strain” were then transformed into one measurement or “summing up-factor”/profile indicating levels of mental load of each individual (expressed as a mean per item= total score/89). A possible measure of differences of score profiles is the sum of differences in scores. This measure makes sense descriptively but does not admit mathematical analysis due to difficulties tied to the use of absolute differences (Nunnally, 1994). In relation to the value tied to each participant, descriptive statistics were calculated for each group.

## *Ethics*

Study 1 affected woman patients suffering from a long-lasting pain syndrome, volunteering to share their experiences of the disease and of life as a whole. Study 2 affected healthy participants volunteering to share their experiences of recovering from a presumed chronic disease. Some of the questions asked during the interviews were potentially upsetting; however both groups of participants were informed about the themes of the semi-structured interview in advance in a letter. The participants were also offered the possibility to turn to the first author for counselling or assistance if they became upset after the interview. The participants of study 2 were also informed that they could contact the Pain Clinic in order to get access to documentation of the results. Study 3 and 4 affected participants suffering from long-lasting pain and women without long-lasting pain. Some of the items of the inventories were potentially upsetting. However, the participants were informed about the content of the questionnaires in general in advance in a letter. The participants were also offered the possibility to turn to the first author for counselling or assistance if they became upset after filling in the questionnaires. The Ethical Committee at the Medical Faculty, Gothenburg University, approved of all study designs.

## **Summary of results**

### *Study 1*

The analysis resulted in identification of four higher order categories labelled *unprotected self*, *compensating strategies*, *increase in mental load* and *reduction of cognitive functions*. The category *unprotected self* was central in data, related to the other categories and was therefore identified as a core concept. *Unprotected self* contained two dimensions representing the developmental conditions of the child and the psychological functioning of the adult women. The core concept and the other higher order categories are presented below, including examples of subcategories pertaining to the content of each higher order category.

The childhood dimension of *unprotected self - overstrained self as a child* mirrors data patterns of having been psychologically *deprived of contact/unsupported* and overexposed to mental load during childhood. Childhood conditions were also characterized by *strain/abuse* and *lack of integrity/symbioses*. The dimension *unprotected adult self* mirrored patterns in the interviews of *difficulties handling affects and stimulation*, *alloplastic difficulties* (difficulties affecting other people and the conditions of life) and a subjective experience of *helplessness* characterizing the adult woman. Simultaneously adult functioning was

marked by *normality* as being sociable and not emotionally withdrawn. Signs in the narrations showed the use of *compensating strategies* as extreme helpfulness, labelled *hypomanic repair*, and a dominating pattern of intense *activity* in order to cope with affects and stimuli. A general tendency to use *dissociative defence* was also indicated by signs in data. *Self-suppression* or unawareness of true needs -a *false self* was used to avoid the notion of being a suffering or a needing person with unmet needs. *Suppressed thinking* was a means of not experiencing the psychological pain potentially present when scrutinising life conditions. Negative mental experiences were, according to patterns in the narrations, also handled/compensated for by redirection of perception from the inner world focusing on the outer world as in *redirection of perception*. At the same time, focusing upon the outer world could mean impairment of protection against over stimulation and *exhaustion*. In a situation of *increase in mental load* fibromyalgia symptoms set on. The increase might, according to patterns in the interviews, be due to psychosocial factors as *disappointment in life/identity crisis* or more 'somatic' factors as localised *pain*. *Obstruction of compensating strategies*, for example, due to ill health or ageing, might also contribute to an *increase in mental load*. Parallel to onset of fibromyalgia symptoms *reduction in cognitive functions* came about. The persistence of the syndrome was, according to patterns viable in the narrations, characterised by qualities of *increase in mental load*, *reduction of cognitive functions* as inability to concentrate and handle stress, psychological functioning of the *unprotected self*, perseverance in using *compensating strategies* or difficulties using them, load from somatic symptoms, fatigue and *protracted insomnia*.

## Study 2

Coding of data patterns (analysis) resulted in the identification of five higher order categories labelled *strong but not enough to be weak*, *increase in mental load - development of fibromyalgia*, *challenge of fibromyalgia*, *decrease in mental load - symptoms remission* and *on parole - strengthened enough to be weak*. The category *on parole - strengthened enough to be weak* was central in data, underlined and crowned a temporal process of the other categories and therefore identified as a core concept. The core concept and the other higher order categories are presented below, including examples of subcategories pertaining to the content of each higher order category.

Data patterns, pertaining to the first dimension of *strong but not enough to be weak*, *strained and benefited as a child*, were mirrored by *overwhelming situation/unprotected child/used child*. Simultaneously, qualities of strain were paralleled with some good for the child to make

use of; *one parent* might have been *loving* or the parental figures might have given the child the opportunity of intellectual *stimulation* or *powerful role models*, if the parents appeared powerful in the area of adult life. *Strong but not enough to be weak* could mean that the women exhibited patterns of *unresolved dependence* in relation to, for example, parental figures. In line with this, interview data also indicated that psychological functioning was marked by being *self-criticising/scared of criticism/easily invaded/overwhelmed*. In the dimension *strong but not enough to be weak*, patterns of impairment of management of negative affect and not handled or self-inflicted exposure to different kinds of strain were also viable in the interviews. Simultaneously resourcefulness in the form of *alloplastic competence/educated/ enjoying professional life* was an obvious quality in the narrations. This was often paralleled with professional success. The women were also characterised by being *capable of receiving help*. Patterns of defence measures of the *strong but not enough to be weak* self, marked by intense activity, dissociation and diversion of attention as in *perceptual defence*, were also present in data. In a situation of further increase in mental load, as *localised pain, invaded/verbal aggression* or *existential threat*, fibromyalgia symptoms set on. Patterns of *exhaustion* of mind and body were also present in data. The challenge of the disease was met by both a vicious circle of strain and helplessness and of mastering skills. Pain and fatigue could be managed through *skills/results from alternative treatment*. The network of support supplied, to some degree, recognition and aid. In a situation of substantial *decrease in mental load, symptom remission* was attained. *Cease of overexertion* of body and mind or *improved family situation-happiness* are examples of this kind of pattern in the narrations. Decrease in mental load was a result from either or both efforts, stemming from the women themselves or some kind of external intervention. The core category *on parole – strengthened enough to be weak*, grounded in data, underlines that change, in the direction of more coherent psychological functioning, has taken place. Recovery appears to be conditional and maintained relying on *personal growth* as more flexible understanding of health needs and also strategies of pacing of activity.

### *Study 3*

#### *The I myself scale*

On the 89 items of the IMS a Chronbach's alpha value was calculated and reached a level of 0.907, indicating the high homogeneity of the scale interpreted in terms of an underlying construct "unprotected self".

"Unprotected self" consisted of items as "I often ignored being tired and

put strain on myself anyway”, “I had always many projects going on at the same time”, “I was very helpful” and “I was a very happy person”. Item wise calculation of contribution to internal consistency resulted in fifteen items being removed from the scale. The alpha-value of the 74 remaining items then reached 0.934. The internal consistency of the removed items reached for 14 of these an alpha value of 0.779. Evaluation of these items (face validity) resulted in the label of “expressed self”. “Expressed self” consisted of items as “I asked others for advice to improve my own life”, “When I was tired I allowed myself to rest” or “I could cry and mourn when I was sad”. The items contributing to “expressed self” were characterised by an active or “well aware” stance regarding emotion (anger or sadness), bodily needs, need for other people, self-care, boundaries and assertiveness. The correlation between the “unprotected self” subscale and the “expressed self” subscale was statistically significant,  $r = -.76, p < .001$ . One –way ANOVAs were performed to find out if the groups differed on these two subscales. The differences were both statistically significant; for the “unprotected self” subscale:  $F(1, 64) = 63.891, p < .001$  and for the “expressed self” subscale:  $F(1, 64) = 43.090, p < .001$ . The fibromyalgia group showed higher “unprotected” scores and lower “self-expressive” scores than did the comparison group. One-way ANOVAs were also performed on item level and in 60 out of 89 items (as shown in the first second and third numerical columns of table 1) the IMS showed statistically significant differences between the groups (Table 1). In this table data from study 3 and 4 are combined.

**Table 1. Items of the I myself-scale and levels of statistical significance of the difference between the fibromyalgia group and the comparison group with long-lasting pain and without longlasting pain.**

<i>Item</i>	<i>M<sub>fibro</sub></i>	<i>M<sub>pain free</sub></i>	<i>P-value a</i>	<i>M<sub>long pain</sub></i>	<i>P-value</i>
I did not listen to my body	4.39	2.83	0.000	3.35	0.001
I often ignored being tired and put strain on myself anyway	4.50	3.33	0.000	3.65	0.002
When I noticed that I got tired I increased my speed	3.25	1.83	0.000	2.41	0.010
I found it difficult to resist demands from those surrounding me	4.22	3.27	0.000	2.91	0.031
I had severe difficulties saying no	4.06	2,97	0.000	3.70	0.225
I had difficulties understanding why I had felt tired	4.00	2.47	0.000	3.09	0.009
I had always many projects going on at the same time	4.31	3.20	0.000	3.26	0.000
I was a person that needed to have something in my hands all the time	4.19	2,47	0.000	3.22	0.002
I had difficulties to understand and accept that I got temporary aches/pain sometimes	4.31	2.10	0.000	3.22	0.001
As a person I was very fast/in a rush	4.44	3.13	0.000	3.39	0.001
I took painkillers to be able to continue an activity	3.06	1.60	0.000	3.09	0.932
I was a person that willingly set to work	4.50	3.67	0.000	3.70	0.002
When I was tired i allowed myself to rest*	1.97	3.43	0.000	2.74	0.005
When I got pain I ignored the pain	4.17	2.33	0.000	3.50	0.023
Many people would have described me as very active	4.36	3.37	0.000	3.60	0.006
I had difficulties "doing nothing" but relaxed through activities e.g. needlework	4.33	2.87	0.000	3.78	0.079
As a person I was very persevering	4.50	3.70	0.000	4.17	0.110
I tried to respect my own need for breaks or rest at home or at work*	2.03	3.27	0.000	2.91	0.003
I took myself time to think my life over*	2.33	3.23	0.000	2.96	0.017
I liked to have a thousand irons in the fire	4.22	3.10	0.000	3.60	0.062
Others would have described me as someone who put my health at risk	3.11	1.97	0.000	2.83	0.421



It was pleasant sometimes to do nothing*	2.56	4.27	0.000	3.60	0.003
I ignored if I got tired when I was busy doing something	4.39	2.93	0.000	3.70	0.004
I never thought about what was good or bad for my health	3.86	2.67	0.000	3.43	0.214
I was there for everybody and everything	4.31	3.27	0.000	3.39	0.001
I felt I had to "finish" something I was doing (and did not terminate to continue later)	4.54	3.23	0.000	3.48	0.000
I willingly received help*	2.43	3.43	0.001	3.13	0.024
I took my own concerns seriously*	2.53	3.53	0.001	3.30	0.026
My life could have been described as "full speed all the time"	4.08	3.00	0.001	3.22	0.012
As a person I was very persistent	4.22	3.30	0.001	4.00	0.397
I easily caught sight of things needing to be done	4.55	3.77	0.001	4.00	0.012
Instead of brooding I started to do things	4.17	3.27	0.002	3.74	0.140
I was very helpful	4.50	3.87	0.002	3.91	0.012
I felt that I managed to do more things simultaneously than other adults	3.72	2.77	0.002	2.61	0.001
I was good at changing and improving my life*	2.50	3.30	0.003	3.43	0.001
If demands from other on me got to high, I clearly stated my case*	1.81	2.57	0.003	2.43	0.020
I was always strongly touched by the troubles of other people	4.50	3.83	0.003	3.48	0.000
My workmates could have described me as super-efficient	4.03	3.30	0.004	3.00	0.000
For me it was important to ponder my own needs*	2.44	3.17	0.005	3.04	0.022
When I had made a decision I always carried it out	4.39	3.87	0.005	3.65	0.001
I asked others for advice to improve my own life*	1.67	2.43	0.006	2.52	0.007
I was very physically active	3.81	2.97	0.007	3.52	0.394
I felt that I had an endless amount of energy/strength	3.91	3.20	0.007	3.65	0.216
I worked faster than others	3.67	2.97	0.007	2.91	0.003
I used to ask others for help when I needed to improve my situation*	1.75	2.53	0.009	2.57	0.007
I used to talk to those close to me about my dreams and plans in life*	2.58	3.47	0.009	3.07	0.180
I could cry and mourn when I was sad*	3.50	4.27	0.011	3.91	0.204
I really stood by other people	4.53	4.00	0.011	3.91	0.004
It felt very important to help other with their concerns/difficulties	4.31	3.73	0.011	3.74	0.022
I put the needs of other adults in front of my own	3.89	3.27	0.019	3.00	0.002

I often discussed with the person closest to me when I needed to change something in my life*	2.78	3.53	0.024	3.30	0.140
I often thought a lot of work tasks lying in front of me	3.64	2.90	0.024	3.30	0.273
I was good at asking for help when needed*	2.22	2.53	0.026	2.91	0.044
I was a very happy person	4.58	4.10	0.033	4.39	0.274
I experienced consideration and respect from adults close to me*	3.25	3.93	0.033	3.70	0.173
As a person I was very active	4.19	3.37	0.035	3.78	0.006
I would have managed to "say no" to too high demands in my work life	2.39	3.10	0.039	2.83	0.230
I always considered it important to have good conditions in my professional life*	3.11	3.23	0.044	3.17	0.877
To me it was important to ponder over myself as a person/my personality*	2.78	3.43	0.045	2.74	0.906
I often thought of myself as a person with lots of endurance	4.05	3.47	0.050	3.65	0.216
I often thought of what I wanted in life*	2.72	3.27	0.070	3.04	0.326
If demands on me from others got to high I got irritated and/ or sad*	2.78	3.37	0.073	3.30	0.124
I always thought it was important that I had good conditions in my private life*	3.53	4.07	0.075	4.00	0.153
I would have managed to "say no" to too high demands from relatives*	2.36	2.87	0.089	2.65	0.377
I kept myself going and was physically active a lot	3.89	3.40	0.094	3.60	0.370
I filled my leisure time with physical training or dancing	3.17	2.63	0.126	2.96	0.596
One could have described me as an optimistic person	4.44	4.10	0.126	4.17	0.196
I made important decisions to improve my life*	2.89	3.40	0.137	3.35	0.202
I tried to look to that I got enough sleep*	3.11	3.60	0.151	3.60	0.141
As a person I was very positive	4.53	4.20	0.153	4.39	0.438
I was careful seeing a doctor when I was stricken by more serious symptoms*	2.72	3.27	0.154	3.00	0.478
I looked both to the needs of myself and to the needs of others*	3.67	3.26	0.182	2.27	0.211
I used to get good ideas about what to in a difficult situation*	4.00	3.70	0.192	3.61	0.099
To pond over my own history of life felt natural to me*	2.86	3.30	0.211	2.83	0.923
I thought to quarrel and to clean the air was OK*	2.72	3.07	0.226	3.00	0.534
To think of plans for my own future felt natural to	3.14	3.47	0.287	3.26	0.712

me*					
I expected consideration and respect from adults close to me*	3.52	3.83	0.334	3.70	0.626
Too many and to high demands from others felt "unjust"*	2.75	2.40	0.342	1.83	0.009
My choice of profession was carefully thought over*	3.03	2.77	0.451	2.91	0.752
I could easily have described myself as a person I was a person that did not hesitate to change employment when I saw a better alternative*	3.72	3.53	0.548	3.30	0.213
I used to ponder about my own life*	3.14	3.30	0.590	3.17	0.911
I often thought of myself as physically strong	3.83	3.70	0.666	3.78	0.877
When I found myself in a difficult situation I sooner or later found a way of handling it*	3.86	3.97	0.674	3.60	0.375
I used to ponder about what I wanted to change and improve in my life*	3.14	3.23	0.736	3.22	0.736
I could express feelings of anger*	3.17	3.27	0.762	3.61	0.217
I decided over my own strength	3.36	3.43	0.801	3.86	0.119
I was in many ways satisfied with my choice of profession*	3.89	3.93	0.865	3.91	0.927
I was an important "resources"-person in my family/among relatives	3.69	3.70	0.986	3.48	0.506

a= difference between the fibromyalgia group and the comparison group without long lasting pain

b= difference between the fibromyalgia group and the comparison group with long lasting pain

\* Indicates that the scale was reversed in order to mirror level/intensity of unprotected self and subsequent compensating strategies

Women diagnosed with fibromyalgia differed from the comparison group without long-lasting pain through, for example, higher scores on items mirroring neglect regarding bodily signals and self-care and lower scores on items reflecting interest in the one-self and plans in life. A Partial Least Square Discriminant Analysis was performed explaining 68.8% of the variance in Y based on 29.4% of the variance in X. The model was validated through plotting the original scores (the x-profiles of each participant). This projection examines the power with which the model is able to separate participants according to group membership based on a summing up of the x variables of each participant. An operating area corresponding to 95% tolerance level was defined by an ellipse in the model. The majority (86%) of the fibromyalgia group was clustered in the right hand sector of the scatter plot whereas the majority (94%) of the group without long-lasting pain was clustered in the left hand sector.

*Goodness of prediction*, the predictive power, of the model was calculated leaving parts of the participants out of the initial calculation and then using this subset of participants to predict group membership. A measure of predictive capability, based on computation of residuals, is calculated called Q<sup>2</sup>. Adding of more Principal Components might increase the *goodness of fit* (explained variance from X in Y) of a model at the same time as the *goodness of prediction* (Q-value) of the model might decrease. In this study the amount of components was decided, based on maximising the predictive power or the Q-value. The value of Q reached 0.558. Aiming at the qualities immanent in the constructed model, variable importance scores (VIP) were computed. Thirty-six variables had a VIP-value that was large enough to be very relevant in “explaining” Y. The original X-variables and the created Y-variables can also be plotted according to loading or weights in relation to the principal components showing the x-variables correspondence to the two groups. As a derivative, the fibromyalgia group could then be substantially described by 27 variables and the healthy comparison group by 9 variables. The traits of the fibromyalgia group could be summarised as themes of perceptual defences, vagueness of self reference, self destructiveness, activity in the service of dissociation, omnipotent (invulnerable) body image and relationships marked by weak boundaries and a quality of “getting invaded” by others. The traits of the pain-free comparison group could be summarised as self-care, not avoiding inactivity/calmness, capability to deal with troublesome mental content and reciprocal benefit in significant relationships.

The profile of items in the scale was investigated and 42 of the items were reversed in order to mirror the profile-level of "unprotected self" and subsequent load from compensating strategies of each participant. The profile levels of the participants were then compared on a group level. On all items but three (as indicated in table 1) the groups differed in the expected direction. That is, the group of women suffering from fibromyalgia showed higher levels of potential or factual mental strain as indicated by "unprotected" psychological functioning and "compensating strategies" than did the control group. As related above in 60 out of 89 items this difference reached statistical significance. When calculating the mean level of strain item-wise and then group-wise (could also be expressed as the group mean level of the profile of 89 items) the group suffering from fibromyalgia showed a level of 3.67 (SD 0.41) on a 5-point scale. The group of healthy controls showed a mean level of 2.93 (SD 0.28). The mean profile levels of each group differed significantly ( $F(64) = p < 0.001$ ).

### SASB

One-way ANOVAs were performed and showed that the groups differed significantly on 8 out of 36 items, a majority belonging to the disruptive part of the love and hate dimension. The scores of the clustered items according to the SASB model were further calculated. Out of 8 clusters the groups showed a significant difference in scores on 4 of these. The groups did not differ significantly from each other on the clusters named *spontaneous self*, *loving self*, *nourishing self* or *controlling self*. Instead the groups differed on *accepting self* ( $F(64) = p < 0.02$ ), with the fibromyalgia group showing a significantly lower score and on *blaming self* ( $F(64) = p < 0.02$ ), *hating self* ( $F(64) = p < 0.001$ ) and *ignoring self* ( $F(64) = p < 0.05$ ), where the fibromyalgia scores were significantly higher.

### Study 4

#### *The I myself scale*

On the 89 items of the IMS a Chronbach's alpha value was calculated and reached a level of 0.879, indicating a high homogeneity of the scale. Seemingly different items could thus be ascribed to a common underlying construct interpreted as "unprotected self". One-way ANOVAs were performed to find out if the two groups differed on single items. In 40 out of 89 items (as shown in the fourth and fifth numerical columns of table 1) the IMS showed statistically significant differences between the groups (Table 1). Women diagnosed with fibromyalgia differed from the comparison group with long-lasting pain through, for example, higher scores on items mirroring being hard-driving or self-neglecting in relation

to bodily signals and lower scores on items reflecting a capacity to receive help, interest in one-self and plans in life.

A Partial Least Square Discriminant Analysis was performed resulting in one statistically significant Principal Component. This component explained from 20.9% variance in X 38.5% of the variance in Y. The model was validated through plotting the original scores (the x-profiles of each participant).

This projection of the individual participants scores on the Principal Component examines the power with which the model is able to separate participants according to group membership based on a summing up of the x variables of each participant. The majority (75%) of the fibromyalgia group was clustered in the upper sector of the scatter plot whereas the majority (83%) of the group with long-lasting pain was clustered in the lower sector. This distribution separates the groups better than would have been expected by chance ( $p < 0.01$ ; “goodness of fit”  $\chi^2$ ).

As described in relation to study 3 a measure  $Q^2$ , of predictive capability, is calculated. As in study 3 the amount of components was decided based on maximising the predictive power or the Q-value. The value of Q reached 0.283. A permutation test of validation was also performed showing a sharp decrease in  $Q^2$ -value as a result of reordering the Y matrix into gradually less correlation with the original model. At a 0 correlation level with the original model the Q-value was negative, showing no predictive power. Aiming at discovering the qualities immanent in the constructed model, variable importance scores (VIP) were computed. A VIP value larger than 1 indicates that a variable was very relevant in “explaining“ Y. Thirty-six variables had a VIP-value that exceeded 1.

The original X-variables and the created Y-variables can simultaneously also be plotted according to loading or weights in relation to the principal component. This way a relationship between the original x-variables (test items) and the dummy variables ( $Y_1$  and  $Y_2$  =groups) can be described thereby showing the correspondence of the x-variables to separation of the two groups along the dimension of the principal component.

The fibromyalgia group could be substantially defined or described by 26 variables and the healthy comparison group by 11 variables. The most influential item defining the fibromyalgia group was “I was strongly touched by the troubles of other people” followed by “I felt I had to finish something I was doing and did not terminate to continue later”. The

comparison group could best be defined by items as “I was good at changing and improving my life.” and “I tried to respect my own need for breaks or rest at home or at work.”

The characteristic traits defining the fibromyalgia group in contrast to the other women with long-lasting pain, could be summarised as themes of “getting invaded” by worries and needs of others exemplified by “It felt important to help others with their concerns difficulties” or “I found it difficult to resist demands from those surrounding me” and an urge to “repair” them exemplified by “I was there for everybody and everything” or “I was very helpful”. Perceptual defences were sometimes used in the form of dissociative or intensive activity patterns as “I worked faster than others” and “When I noticed that I got tired I increased my speed”, vagueness of self reference and an omnipotent (invulnerable) body image as “I had difficulties to understand and accept that I got temporary aches/pain sometimes”. The traits of the comparison group with long-lasting pain could be summarised as a more realistic body image as “I tried to respect my own need for breaks or rest at home or at work”, self-care – interest in the own person as “I took my own concerns seriously” including conditions of life as “I was good at changing and improving my life”. Further, inactivity or calmness were not avoided and a capacity to deal with troublesome mental content was paired with support and benefit as “co-thinking” in significant relationships exemplified by “I asked others for advice to improve my own life”.

The profile of items of the IMS-scale was investigated. Forty-two of the items were reversed in order to mirror and compare profile levels or levels of "unprotected self" and subsequent load from compensating strategies between the two groups. On all items but ten the groups differed in the expected direction. That is, the group of women suffering from fibromyalgia reported higher levels of potential or factual mental strain during the phase of life before onset of fibromyalgia symptoms, than did the comparison groups during the corresponding phase. When calculating the mean profile level of impairment of self-protection against a too high level of mental load item-wise and then group-wise (could also be expressed as the group mean level of the profile of 89 items) the group suffering from fibromyalgia reached a level of 3.67 (SD 0.41) and the corresponding figure for the group of women with long lasting pain reached a level of 3.21(SD 0.40) ( $p < 0.001$ ). The mean profile levels of each group differed significantly ( $F(57) = p < 0.001$ ).

### *SASB*

The scores of the clustered items according to the SASB model were calculated. One-way ANOVAs were performed to find out if the two groups differed on these clusters.

Out of 8 clusters the groups showed a significant difference in scores on 1 of these, the fibromyalgia group showing a significantly higher score on *controlling self* ( $F(64) = p < 0.05$ ). This cluster is composed by items stating interest in self-control regarding temper, goals in life, obligations, goodness and adaptation to norm/correctness. The groups did not differ significantly from each other on the other clusters; *spontaneous self*, *accepting self*, *loving self*, *nourishing self* or *blaming self*, *hating self* and *ignoring self*.

### *SF-36*

All scales were transformed by the SF-36 scoring program to range from 0-100, with higher scores indicating better health. From the perspective of a physical health dimension the groups were similar regarding the ability to perform work or physical activities (PF) and regular activities or work due to physical health (RP). They were further similar regarding level of pain, including functional limitations due to pain (BP). Differences emerged regarding reported health and expected future health (GH) ( $p < 0.05$ ), women with fibromyalgia reporting worse health than the comparison group. Regarding mental health, women with fibromyalgia reported worse quality of life in the dimension of fatigue or feeling worn out (VT) ( $p < 0.001$ ). The fibromyalgia group also reported worse psychological well being (MH) ( $p < 0.005$ ), and greater difficulties regarding work or regular activities due to emotional problems (RE) ( $p < 0.05$ ). They further reported more of limitations regarding social life connected to emotional and psychical health status (SF) ( $p < 0.005$ ).

A comparison between the two groups on the two main dimensions of the concept of health, Physical Health (PCS) and Mental Health (MCS) revealed on the one hand equal physical health-scores and on the other hand women with fibromyalgia exhibiting statistically significant lower mental health-scores ( $p < 0.005$ ).

### **Discussion**

The aims of study 1 and 2, taken together, were to illuminate psychological functioning and the process of development, maintenance



or recovery from fibromyalgia in women presently or once diagnosed with the syndrome. Two, both different and similar, self-structures were identified, belonging to the two groups respectively. The women developing and maintaining fibromyalgia showed a self-structure described as *unprotected self*. Having an *unprotected self* meant having been exposed to high levels of strain as a child at the same time as sufficient amount of support was unavailable. In adulthood the women, developing and presently maintaining fibromyalgia, exhibited a ‘candle in the wind’-pattern of difficulties in handling affects and stimulation. Reasonable attention towards e.g. health issues was missing. Simultaneously, they were easily invaded by the problems and worries of others. Autonomy and a reasonable clear sense of a self were not sufficiently developed. A dominating pattern was also difficulties regarding necessary effort in relation to affecting the conditions of their lives. The vulnerabilities and difficulties of the women were compensated for through strategies as a stance of extreme helpfulness to other people and patterns of keeping oneself busy/intense activity.

In the case of the recovered group data patterns showed similarities to the “unrecovered “ group such as difficulties handling affects and stimulation. In the background of both the self-structures *unprotected self* and *strong but not enough to be weak self* were high levels of strain in childhood but in the case of *strong but not enough to be weak self* these patterns were combined with elements of love or powerful role models for the child to make use of. In adult life the “recovery group”, in contrast to the other group, showed a marked capacity regarding affecting conditions of their lives. They were capable of receiving help and getting a good education/professional success. The group simultaneously exhibited that they were scared of criticism, easily invaded by others and like the other group they exhibited difficulties making use of affects as fear in order to regulate levels of mental or physical load. The two parts of their selves, the strengths and the weaknesses, were held apart by exhausting high-speed activity-patterns or other dissociative defences. The vulnerable parts could be seen as deserted or covered by the competent parts.

In a situation of increase in mental load such as loss of full health/ageing or increased demands from the work place, both groups developed cognitive difficulties and symptoms of fibromyalgia (generalised pain and pronounced fatigue). The passed or ongoing phase of fibromyalgia was in both groups marked by a maintained high level of mental load in terms difficulties using compensating strategies or still employing high speed activity patterns, cognitive difficulties handling stress or concentrating,

load from somatic symptoms, fear due to undiagnosed pain and an altered situation in life as sick-listing. In the case where the process ended in recovery, the women simultaneously experienced different kinds of support counteracting hopelessness and despair. Most of them described a good relationship with a good doctor. The women that later recovered also used their well-developed alloplastic skills to seek information about their condition. They further benefited from and developed skills in relation to alternative treatments. From these treatments they achieved gaps in pain. However, these improvements in relation to symptoms were immediately made use of and balanced out by increase in activity. This way, the disease was not a stage that had passed.

Not until in a phase of a substantial decrease in mental load the recovery group experienced that the symptoms gradually disappeared. An additional somatic disease or retirement might mean cease of over-activity constituting a starting point of gradual remission of symptoms. The self-structure and stage of recovery *on parole - strengthened enough to be weak* underlines that recovery was conditional and relied on a change in psychological functioning. Health was maintained by ways of living as refrain from being overactive and was also safeguarded through a life lived on a personally relevant low level of strain.

#### *Tentative theory*

An interpretation of the present results of study 1 and 2 is the forming of a tentative theoretical model (hypothesis) of the development of two self-structures (self-regulatory styles) that interacts with and responds to levels of mental load. This kind of analysis relies on the third step of grounded theory analysis aiming at integration of the emerging categories into an explanatory theory. The relationships between the categories, on which the theory relies, reflect coded data patterns, and resulted in identification of the two self concepts; *unprotected self* and *strong but not enough to be weak*, the latter later in the process transformed into the self structure (and phase) *on parole – strengthened enough to be weak*. The self-concepts had not a simple cause and effect relationship with the other higher order categories constituting the temporal processes but rather a reinforcing and partly causal relationship to the other higher order categories.

The hypothesis, based on data patterns from study 1 and 2, is that there is a psychosomatic process of disregulation. Development of disregulation means having been psychologically deserted and/or overexposed to mental load in childhood. In the case of an *unprotected self, alloplastic difficulties* and a subjective experience of *helplessness* characterised the

future adult. In the case of *strong but not enough to be weak/strengthened enough to be weak*, this was paired with elements of love and or powerful role models for the child to make use of, resulting in alloplastic competence in adult life. A general tendency to use *dissociative defence*, meaning also pronounced corporeal and mental strain, was present in both groups. Later in the process, the individual became a victim of not being able to cope with the exposure to a further increase in level of mental load. Mental load added to an already high level, or having escalated at the time of onset of fibromyalgia symptoms was due to psychosocial factors as crisis, *abuse/aggression in a close relationship* or more 'somatic' factors as localised *pain*. *Obstruction of compensating strategies*, for example, due to ill health or ageing, could also cause an increase in stimulation from the psyche itself. Thereby, overstimulation and *reduction in cognitive functions* came about. To maintenance of the syndrome contributed a 'vicious circle process' including qualities of *increase in mental load, reduction of cognitive functions*, psychological functioning marked by the difficulties of the *unprotected self* or the *strong but not enough to be weak*-self. The 'vicious circle' could include perseverance in using an exhausting defence style of being overactive or difficulties in using this defence style, load from an altered life situation, somatic symptoms, fear in relation to symptoms, fatigue and *protracted insomnia*.

In relation to the group recovering from fibromyalgia the third step of grounded theory analysis meant appointment of a core concept, labelled *on parole –strengthened enough to be weak* underlining a process of change; starting to use psychological strength in the service of acknowledgement of vulnerability meaning careful management of health needs, necessary to preserve a recovery on parole.

This tentative interpretation of the processes of the two groups respectively, grounded in data, depicts two psychosomatic processes, regarding both groups, of initially inflexible defence-structures, responding to variations in mental load. In the case of recovery, decrease in mental load was accompanied by a more flexible self-regulation securing absence from symptoms.

#### *To recover or not?*

The women recovering from fibromyalgia were characterised by obvious alloplastic competence. Alloplastic competence had simultaneously no immediate relationship to recovery from fibromyalgia. The women did not lift themselves by the hair or pulled themselves together, in order to recover. A hypothesised relationship between alloplastic competence,

decrease in mental load and recovery could be discussed in terms of a more direct access to feelings of hope/optimism and relief when opportunity knocked in the form of a *decrease in mental load*. A dynamic of improved conditions of life (optimism) and self-confidence might be illustrated by results from an experimental design (Norlander, Bood & Archer, 2002) indicating that a high level of positive affectiveness seemed to be a prerequisite for successful coping with stress in terms of cognitive performance. From a more theoretical perspective on self-regulation (Taylor, 1992), the capacity to plan and the notion of being able to affect the conditions of your life, could work in the opposite direction of psychosomatic outburst, due to competence in the area of cognitive processing of affects. Cognitive processing playing a role in influencing the level of symptoms in fibromyalgia gets support by the finding of Barbour (2000) that getting information about fibromyalgia, through books videos etc, was rated by individuals with fibromyalgia as the most efficient alternative treatment. Runners up were aromatherapy, support groups, heat and massage. Improved and/or more integrated mental functioning might, in the recovery group of the present study, have been promoted by the documented decrease in mental load. The category *personal growth* also mirrors a similar phenomenon present in data, in connection to preservation of absence of symptoms.

The maintenance of fibromyalgia in study 1 might be interpreted in terms of the prerequisites of neutralising interactions between unprotected psychological functioning, mental load and reduced cognitive functioning not being at hand. Effects from this kind of 'vicious' interactions could be supported by findings from an experimental design by Davis, Zautra and Reich (2001) reporting that when compared to women with long-lasting orthopaedic pain, women with fibromyalgia were found to have fewer positive affect resources, positive affect also being an inverse predictor of pain level in the fibromyalgia group but not in the control group. Women with fibromyalgia further experienced a larger and more prolonged increase in pain when they were exposed to a combination of different stressors. The groups did not differ regarding base-line level of pain or pain tolerance per se. In study 2 both the deeds of the participants and the help from the surrounding world worked in the opposite direction of the qualities of a maintained high level of mental load. The participants, for example, helped themselves by efficiently and successfully seeking professional support in relation to the symptoms, thereby experiencing symptoms relief and some degree of control. The women often also had the economic resources of seeking this kind of help. One aspect of vulnerability connected to the state of fibromyalgia in study 1 was the deterioration of conditions of life, preceding onset of fibromyalgia and

resulting from fibromyalgia. In study 2, signs in data indicate that the deterioration has been annulled or neutralised through significant positive change in the life conditions and/or through other kinds of decrease in mental load as through *talent/skills* or *cease of overexertion* of body and mind. In study 2, the mental load might also be neutralised through the difficulties of the *strong but not enough to be weak* self-structure being transformed through *personal growth*, or compensated for through the creation of more advantageous living conditions. Bearing in mind that alloplastic competence identified in the recovered group was one of the most obvious differences in personality structure when compared to the women maintaining generalised pain, *alloplastic difficulties/helplessness* identified in relation to maintenance could specifically be looked upon as contributing to the described difficulties during the state of fibromyalgia. This interpretation is also supported by the fact that the women of study 1 who had had progress regarding their symptoms (gaps in pain lasting 1 hour to 7 years) also showed greater alloplastic competence and exhibited less helplessness than the other participants of study 1.

#### *Quantitatively mirrored qualities*

In study 3 and 4 the aim was, based on psychometrical instruments, to map psychological functioning potentially resulting in mounting of an intolerable amount of mental load (*unprotected self*), in women with fibromyalgia. Women suffering from fibromyalgia, women without long-lasting pain and women with organically explained long-lasting pain were compared. The inventories developed or chosen, based on qualitatively generated data-patterns, mirrored self-regulation/self-image in a phase of life before onset of generalised pain and current self-regulation/self-image, respectively. As a bi-product, level of degrees of having lived an “unprotected life” in a phase of life prior to onset of generalised pain was calculated and described. This bi-product was made possible through the scale (IMS) showing high internal consistency. A method of reduction of the amount of variables paired with discriminant analysis (PLS-DA) of the developed instrument (IMS) was employed and indicated that it was possible to discriminate between the fibromyalgia group and the two other comparison groups according to patterns of psychological functioning. On behalf of the fibromyalgia group the appearing pattern could be summarised as difficulties in the area of defining the self and subsequent health needs. The pattern also included omnipotent self-evaluation and perceptual defences regarding bodily signals together with elements of weak boundaries to other people, self-neglect and self-destruction. Intense and high speed activity patterns and avoidance of breaks, rest and “piece and quiet” replaced or were equivalent to more “mentally” executed means of dissociation. A quality of getting invaded

by the needs and demands of others and acting in line with these expressed needs was also present. The comparison groups on the other hand could be described in terms of self care including a realistic body image paralleled with reflection and “time to think” without avoidance of potentially painful mental content. A capacity to work on the conditions of life was combined with a pattern of receiving help and “co-thinking” from significant others, using them as “auxiliary ego”-functions.

Besides discriminant analysis means of single items of the IMS were compared, between the groups. Based on retrospective report, these differences depicted avoidance of negative affects, lack of self assertiveness paired with a “hypomanic” self-reference and “inconsiderate” experiences from close relationships on behalf of women developing fibromyalgia in contrast to pain free women. In contrast to both pain free women and the other comparison group, alloplastic difficulties including not using other people as “co thinkers” or auxiliary egos characterised women with fibromyalgia. Based on “residual items” from the discriminant analysis women with fibromyalgia differed from the other pain group through showing a self-image of endurance/high activity level and disregard of bodily signals.

Calculated total scores of “unprotected self”, mirroring overall degree of exposure to accounted for factual and potential strain before onset of generalised pain or 10-15 years back, showed that the fibromyalgia group had lived their lives at a higher level of strain than had the comparison groups. The mean of their group profiles covering all 89 items was situated close to 4 on a 5-point scale. The corresponding figure of the comparison group without long lasting pain was situated below mean score 3. The mean group profile of the other pain group was situated just above mean score 3. This result corresponds well to Wentz, Lindberg and Hallberg (2004a) documented data patterns of “adult functioning characterised by impairment of self-protection against a too high level of strain” (p.710) due to the functioning of an “unprotected self”. Women with fibromyalgia were compared to women with organically explained long-lasting pain regarding physical functioning, bodily pain and other dimensions of health related quality of life. The result from SF-36 indicated that women with fibromyalgia and the comparison group currently experienced a similar amount of physical difficulties including level of pain. This was paired with reported less well-being in all the psychological and social dimensions of SF-36 including lower scores regarding vitality, on behalf of women with fibromyalgia. A pattern of worse psychological health status in patients with fibromyalgia than in other pain patients, is confirmed by the finding that the syndrome of

fibromyalgia was connected to both impaired physical and mental health in contrast to myofascial pain syndrome that was connected mainly to impaired physical health (Tuzun, Albayrak, Eker, Suzay & Daskarpan, 2004). In line with both these findings Henriksson (1995) reported that patients with fibromyalgia, when compared to other patients with pain, showed higher impact in the psychosocial dimension at the same time as the impact in the physical dimension was lower. The result might further confirm a pattern documented by Wentz, Lindberg and Hallberg (2004a) of a notably high level of mental load during the state of fibromyalgia.

### *Qualitative and quantitative pieces together*

In study 1 a pattern of dysfunctional self-regulation in adult life before onset of fibromyalgia pain was identified. Sufficient attention towards the self and, for instance, health issues was missing. Parallel to this the women were easily invaded by the concerns and worries of others. A dominating pattern was also difficulties regarding necessary effort in relation to affecting the conditions of their lives. These vulnerabilities were compensated for by strategies as a stance of extreme helpfulness to other people and patterns of keeping oneself busy/intense activity. The patterns that emerged through psychometrical testing confirmed a connection between development of fibromyalgia and a lack of attention towards the corporeal and existential self, including limited effort/skill regarding affecting the conditions of life. The women that had developed fibromyalgia might on one hand report similar skills as the comparison groups regarding getting good ideas on what to do in a difficult situation and on the other hand reporting that they placed less importance on pondering their needs and had less skill regarding life improvements. They also reported less experience getting help from others and less effort to get help making good plans for their own life. The items of the IMS on getting help from others or using them as 'co thinkers' clearly separated the fibromyalgia group from the comparison groups and might thereby make viable an 'extension' of a childhood pattern from study 1 on insufficient support and deprivation of contact (Wentz, Lindberg & Hallberg, 2004a). The differences between women with fibromyalgia and the comparison groups were less pronounced regarding dealing with life 'on their own'. This specific pattern might confirm the quality of having an inflated self-image regarding 'strength' and 'being in control' in adult life, also reported by Wentz, Lindberg and Hallberg (2004a). The IMS could be said to contribute to depth and nuances regarding psychological functioning identified through qualitative method. The patterns of women with fibromyalgia being easily invaded by the difficulties of others identified through qualitative method were fully confirmed. This was also the case concerning patterns of pronounced helpfulness to other people

and proneness to be self-loading, keeping oneself very busy or having an intense activity style.

The suggestion based on naturalistic inquiry that the state of fibromyalgia holds the quality of a maintained specific high level of mental load not only 'explained by' physical limitations, somatic symptoms or 'a life with pain', was also supported by the psychometrical pattern that emerged from SF-36.

#### *Methodological considerations*

The choice of grounded theory was guided by the research question, which aimed at individual, and interpersonal processes in relation to a third process - the development and recovery from fibromyalgia. Grounded theory was also chosen based on preparedness to form a theory or a model from the emerging concepts. The interview guide employed was inspired by clinical psychological procedures that aimed at mapping, for example, the onset and course of symptoms, activity-style, symptoms management and interpersonal relationships. In the analysis of the interviews a steppingstone was a psychoanalytic or psychodynamic framework together with the view that that currently employed psychoanalytic theory and concepts or psychodynamic theory, on psychosomatics or psychopathology, were not sufficient in order to explain the area under study.

When using grounded theory, a critical point is having a clear stand on the relationship between data and abstraction (formation of categories and explanatory models). According to Glaser (2002) the doings and meanings of the informants are not supposed to be described but abstracted from in the service of discovering an underlying cause of behaviour. The qualities, in the narrations, were supposed to be best captured using both codes based on psychological terminology (*in vitro codes*) and labelling based on words or expressions from the informants (*in vivo codes*). Examples of *in vitro codes* referring to psychological entities were "directing aggression inwards" or "being omnipotent". The *in vivo* codes labelled observations in terms of 'difficulties sleeping' or 'increased work'.

#### *Sampling effects and transferability*

The aim of the present studies was to gain a deeper understanding of psychological functioning and psychosocial conditions from the angle of development, maintenance and recovery from fibromyalgia. Accordingly to start with, women suffering from fibromyalgia were strategically sampled and interviewed in depth. Simultaneously, characteristics of the



sample and transferability of the results need to be estimated. The women participating in study 1, to some degree, selected themselves to the study, through a certain amount of initiative. The majority of participants were recruited from healthcare. They were patients, seeing a doctor either due to fibromyalgia or to other complaints/disease. It was up to the woman herself to get in contact with the research group. Some of the younger or more educated women, as well as the women that had experienced full remission of symptoms but later got the disease back, were not recruited from health care but in connection to the advertisement in the paper looking for women to study 2. These women were therefore also 'self-selected' through having to take the initiative to get in touch with the research group. The sample of study 1 showed, besides the qualities accounted for in the result, to be fairly homogeneous regarding being or having been well established on the labour market. Further, few of the participants were involved in the fellowship of a fibromyalgia society.

Sampling disconnected to a 'fibromyalgia setting' needs to be taken into account when considering transferring the results. It might mean that the sample of study 1 represents more of a less 'disappointed' or demoralised phase of development of the syndrome or less disillusioned subgroup than samples of known current patients, contacted in a more direct fashion from a physiotherapy group for patients with fibromyalgia or from social insurance settings. In the study by Hallberg and Carlsson (1998) the women participating were approached by the researchers in a hospital or social insurance hospital setting and no initiative, except for informed consent, on behalf of the woman herself was required. The results (or the theoretical model) of the Hallberg and Carlsson (1998) study might reflect this other sampling technique. The women were described more in the dimension of passivity and persistence of symptoms was viewed partly as derivatives of the dynamics of secondary gains and reinforcement of the sick-role. This emphasis on passive needs is also the only obvious contradiction between the present description of psychological functioning, characterising the persistence of syndrome of fibromyalgia, and the result reported by Hallberg and Carlsson (1998). The present result instead describes increased vulnerability of psychological functioning in the form of *reduction in cognitive functions*, *increase in mental load* and load from somatic symptoms, after the onset of fibromyalgia symptoms. The differences between the conceptualisation of data patterns of the present results and the Hallberg and Carlsson (1998) study might be regarded as partly due to diverse possibilities of a strategic sampling (heterogeneity). Data patterns of the present sample (study 1) showed marked dependence in the domain of sociability and also signs of an active stance. These characteristics of the present sample

were pronounced enough to contribute to interpretation regarding the phase of maintenance as mainly marked by vulnerability and not by the sick-role. The pattern reported by Mannerkorpi (1999) that a subgroup of women with fibromyalgia use all their available energy to manage to live their lives 'as if healthy' meaning, for example, working full time, resembling the present results (study 1 and 2), also speaks in favour of the present interpretation of the patterns in data. Also the interpretation of the process of recovery, preceded by a decrease in mental load as pictured in study 2, speaks in favour of an interpretation of psychological vulnerability interacting with levels of mental load being effective in maintenance of fibromyalgia.

Study 2 deals with a small minority of women once diagnosed with fibromyalgia. This has to be taken into account when considering transferability of the results. The sample was, due to limited accessibility, small and also not strategically selected. At the same time, the sample held some qualities of heterogeneity according to age, education and professional background. The sample was also homogeneous according to patterns of being or having been well established on the labour market, having had reasonably stable family conditions during adult age, and being characterised by an active stance on own initiative having contacted the research group. If women with pronounced lesser ability to receive help and with less of an alloplastic capacity recover from fibromyalgia, not much is known about them from this study. When comparing the results from study 2 on psychological functioning to documentation on patients with fibromyalgia who have recovered (Scammell, 2001) or had a positive outcome on rehabilitation measures (Keel, Bodoky, Urs & Müller, 1998) the picture of psychological functioning marked by 'transformation' in the direction of increase in self-care is the same.

Sampling procedures, connected to grounded theory, are designed aiming at mirroring different alternative interpretations, along the process of emergence of conceptualisation of data and emerging preliminary theory. Through constant sampling decisions different alternative interpretations are ruled out or further investigated. For example hypotheses on 'the sick-role' as an important factor in maintenance of the syndrome might be tested through interviews with professionally very active women suffering from fibromyalgia. A complementary attempt in the service of testing hypotheses through sampling was the decision to explore the lived experienced of women having experienced full remission of symptoms as in study 2.

In order to do full justice to the narrations of the 29 women and further improve the understanding of the area under study: psychological processes expressed by women diagnosed with fibromyalgia, analysis of the present

interview data could be carried out a second or even more times. Such procedures should be regarded from the angle of the complexity of the area under study, rather than from an angle of insufficient reliability of the present interpretation. Future interpretations should be viewed as complementary (Malterud, 2001) to the present. According to Malterud (2001) ‘Validation through consensus or repeatability is seldom adequate in qualitative research (p. 484)’. In this thesis instead a principle of traditional quantitative methods and qualitative research methods being complementary, in order to improve understanding of psychology in medicine (Malterud, 2001), is applied. The results from the qualitative studies could answer questions on individual and interpersonal processes and the results from the quantitative studies could answer questions on whether the identified features and nuances are specific or not for the group or groups under study or not. Consequently, from interviews, inductively created abstractions were tentatively translated into an inventory on “unprotectedness” prior to onset of generalised pain (IMS). The IMS was analysed based on the research question on sifting the women with fibromyalgia from the comparison groups. IMS was in order to further examine the tentative model from study 1 also supplemented with two other scales measuring current self-regulation (SASB) and current subjective health (SF-36).

#### *Recall as a source of information*

In the present studies 1 and 2 recall on life-experiences and childhood conditions is one of the sources of data. Other sources of information (recurrent patterns) in line with clinical psychological methodology are, for example, how a certain topic is dealt with or how a question is answered. The state of fibromyalgia is in the present results pictured as marked by vulnerability and influenced by load as from conditions of life, somatic symptoms and psychological problems. The question arises whether patterns of recall on having experienced high levels of strain at a young or younger age is foremost connected to a life characterised by protracted present pain and depressed mood, and therefore not important expressions and signs of a strainful life history. Depressed individuals are known to more easily recall more negative events. Whether this is due to having experienced more negative events or whether their mood influences their interpretation is not known (Cristiansson, 2002). On the other hand, recall on significant past events is by Brewin, Andrews and Gotlieb (1993) not assessed as affected by mood state, also stating that depressed mood is not known to create systematic distortions of experiences from early life. From the present results based on data patterns grounded in interview data regarding a high level of strain at an early age, both women presently suffering from generalised pain and women presently recovered reported on the same qualities. The groups

differed with respect to patterns of women without generalised pain reporting more positive experiences including better economic conditions simultaneously corresponding to more reported 'hard facts' as having got a better education.

In study 3 and 4 the question of present pain and hypothesised subsequent depressed mood affecting recall and response set is mirrored by the result of study 4. Comparable levels of happiness prior to onset of pain are reported together with a more 'generous' attitude towards others and self-neglecting activity patterns on behalf the fibromyalgia group. In this context the median age differences between the two groups with pain must be taken into account. The women that developed fibromyalgia, unlike the women with organically explained pain, might be characterised by onset of pain in an earlier phase of life when they might have been responsible for small children. Their self-report pattern might therefore reflect these differences in life conditions and not "unprotectedness". Simultaneously women with fibromyalgia showed a higher score also on an item like "I put the needs of other adults in front of my own" not likely mirroring duties tied to motherhood. The denomination of the questions of the IMS must also be taken into account. The questions mirror, not in particular, socially undesirable or desirable variation in "lifestyle". For example to be "there for everybody and everything" could be viewed either from the angle of being careful and sensible or capable and dutiful. The answers must therefore be considered as reasonably likely to reflect a genuine standpoint of the individual.

#### *Women but seldom men*

Women are 7 times more likely than men to develop fibromyalgia (Wolfe, Ross, Andersen, Russel & Herbert, 1995) and the results of the present studies indicates that development of fibromyalgia is connected to specified self-regulatory styles that respond to variations in mental load. This makes it important to approach the question of differences between the sexes regarding self-structure and self-regulation. One documented difference is the 'proneness-profile' of women of response to specific trauma by development of posttraumatic stress disorder (PTSD). According Breslau (2002) trauma that involves assault between individuals (for example robbery, rape or physical abuse) is six times more likely to result in development of PTSD in women than in men. When it comes to other kinds of trauma as life-threatening illnesses, car accidents or natural disasters, the rate of reacting with PTSD-symptoms does not differ between the sexes. In this context it is important to underline that interpersonal strain is among the strains present in the backgrounds of the women documented in study 1 and 2 and is also

condensed into higher order categories pertaining to the data-pattern theories. Interpersonal strain as *abuse/aggression in a close relationship* or *invaded/verbal aggression*, are also components of the *increase in mental load* that is accompanied by the onset of fibromyalgia symptoms. This proneness to react to traumatic mental load related to interpersonal exchange by not being able to integrate and work through, might therefore also be valid for the childhood patterns of cumulative trauma conceptualised in *unprotected self* and *strong but not enough to be weak*. Cumulative trauma was by Kahn (1963), defined as the failure of the mother to act as a protective shield towards the child in relation to too big an amount of mental load tentatively illuminating the dynamics of the '*unprotected self*'.

For the gender specificity of self-regulation marked by hypomanic repair, as identified in all four of the present studies, speaks the observation that preschool girls, contrary to preschool boys, respond to unfavourable conditions after their parents' divorce, by being overly responsible to peers (Page, 1998) or to a parent (Page et al., 2001). Further Blatt (1995) suggests a disruption of normal development marked by excessive preoccupation with relatedness at the expense of self definition being more frequent in women. In favour of hypomanic repair as a gender specific self-regulation speaks tentatively also the specific female profile of stress response, suggested by Taylor et al. (2000). This response appears in females as a complement to the 'fight or flight' pattern, employed by both sexes, and is manifested by caring for others and closeness to others - 'tend and befriend'. According to the researchers these patterns might selectively have evolved to maximise the survival of the woman herself and the offspring. The befriending pattern promotes the affiliation of the woman with social groups to reduce risks. The tending (attachment/care-giving) part of the pattern also down-regulate the hypothalamic-pituitary-adrenocortical (HPA) responses to stress in both the mother and the offspring (Taylor et al., 2000). The observation that girls and boys respond to traumatic experiences in different fashions; girls, in contrast to boys, preferably by dissociation (Arver, 2001), supports both a gender specific modus of reaction and the emphasis on a perceptual defence style including dissociation present in all four studies.

#### *The origin of adult self-regulatory measures*

For a connection between the conceptualised data patterns of study 1 and 2 regarding childhood conditions of high levels of strain combined with low levels of support, and a *strong but not enough to be weak* functioning/use of specific *compensating psychological strategies* in adulthood, speaks the findings of Almquist, Janson and Broberg (2002).

These researchers described psychological functioning in children presently living in families where the mother is currently physically abused by the father or the stepfather. The children got both overstrained at the same time, as sufficient parental support was unavailable. The children's strategies of handling high levels of strain and emotional abandonment are equivalent to the patterns of psychological functioning, found in study 1 and 2. For example, data pattern of extreme helpfulness mirrored by *hypomanic repair* of the present results is identified on behalf of the children (Almquist, Janson & Broberg, 2002). They are described as very loving, attentive and comforting towards their mothers. Further, the children in the report were found to be 'overly dependent on parents'. Other examples of the resemblance in psychological functioning are the patterns of *activity, suppressed thinking* and *redirection of perception* as means of avoiding difficult notions also exhibited by the children. The overstrained children themselves, for example, stated that they tried 'not to think' and also exhibited patterns of constantly keeping themselves busy and being very active. The children were at the same time able to concentrate and accomplish tasks, as were the women later developing fibromyalgia. Almquist, Janson and Broberg (2002) further relates that in situations as when the child tried to rest and avoidant strategies as being very active were not used, psychosomatic reactions on behalf of the children were identified. Sleep disturbance of the children was also documented.

The patterns of psychological functioning reported by Almquist, Janson and Broberg (2002) could, besides supporting contextualisation of specific adult functioning with childhood conditions, also be viewed from the angle of psychological strategies specifically related to currently living with unhandled mental content (experiences, affects etc) without hope or prospect of handling this content. The reported situation of the individuals/the children (Almquist, Janson & Broberg, 2002) is of not expecting or having experienced a 'post-traumatic' phase. Overstimulation and lack of sufficient support is an ongoing ordeal. Such a clear parallel between psychological functioning of children unsupported and overexposed to mental load and psychological functioning, in a context of development of fibromyalgia, in adults also raises questions on specific arrests in development of necessary psychological skills, in the psychoanalytic tradition named ego development.

Another connection between fibromyalgia and mental strain in early years might be indicated by the profile of self-regulatory measures documented in all four studies. From research on the trauma of child

abuse, interference with the child's access to a sense of self -a so called "impaired self-reference" is described (Briere, 1992). This impairment also means less ability regarding self-comfort leading to overreactions to stress and painful affects. Briere (1992) further portrays unawareness related to the own needs paired with proneness to tune into the experience of others. Impairment of the self-reference is partially ascribed to dissociative functioning also identified in the present studies. The concept of trauma could in the present context be meaningfully elucidated by Kahn (1963) separating "chock trauma" from "strain trauma" and, in the case of "strain trauma", pointing at the situation of a small child when the primary caretaker fails, to act as an "auxiliary ego" in relation to mental strain. Resulting from this, both self-awareness (based on the body ego) and coherence of the self are insufficiently established. Simultaneously selective ego functions are accelerated in growth and used defensively. Marked infantile dependency is further maintained but dissociated from asserted independence. The phenomenon of strain trauma (Kahn, 1963) relying on insufficient access to auxiliary ego resources, might also shed light on insufficient use of others as helpers or "auxiliary egos" in adult life as documented in study 3 and 4.

#### *Localised pain and defence-style*

Fibromyalgia pain is often preceded by localised pain. According to Bengtsson et al.(1986) 87% of patients with fibromyalgia reported that they initially had localised pain. Henriksson, Carlberg, Henriksson, Kjällman and Lundberg (2004) related that 80% of a group of patients with fibromyalgia stated that their wide spread pain had gradually developed from localised pain. Based on the present results it could be suggested that localised pain, besides being a mighty stressor added to an already high level of mental load, could also be regarded as a factor that challenges the vulnerable self-regulation of the *unprotected self* or the *strong but not enough to be weak* self. Pain has according to Melzak and Casey (1968) three major psychological dimensions: a sensory-discriminative dimension, a motivational –affective dimension and a cognitive evaluative dimension. A translation in part of these psychological aspects of pain is that pain forces the attention of the individual from the outer world towards the own person or 'the self'. This function of localised pain directly militates against the suggested defence measures of the present results, exactly aiming at diverting attention from both the body and the self-representation of the individual, mainly in the service of not experiencing vulnerability. Qualities of repression of the self-representation (study 1 and 2) similar to the findings by Jacobsson (1989) employing the Defence Mechanism Test modified DMTm-technique and the defence measure of *redirection of perception* both

confirmed in study 3 and 4 mirrors the, by localised pain, most obviously challenged self-regulatory measure of the tentative explanatory models of study 1 and 2.

### *Fibromyalgia pain –an indicator?*

Psychological tensions (Henriksson, 1995) or stress (Waylonis & Heck, 1992) have been documented to be effective in an increased level of fibromyalgia pain. Davis, Zautra and Reich (2001) employed experimental design and found that stress-related increases in pain were exacerbated by additional negative mood induction among women with fibromyalgia but not in the control group also suffering from long-lasting pain. Women with fibromyalgia also, in contrast to the control group, displayed a decrease in positive affect in the context of pain during stress. Felson and Goldenberg (1986) have documented that patients with fibromyalgia might ascribe a major role to life events in the exacerbation or alleviation of symptoms. Montoya, Larbig, Braun, Preissl and Birnbaumer (2004) further found, in a group of patients with fibromyalgia, that the presence of a significant other decreased pain sensitivity both regarding brain activity as measured by magnetoencephalography and regarding subjective ratings. This pattern could not be identified in a control group consisting of patients with migraine.

About one third of patients with fibromyalgia experience gaps in pain (Henriksson, 2002). Unlike the frequency of pain in a group of patients with neck-, shoulder- and back-pain the frequency of pain in a group of patients with fibromyalgia showed to be affected by self-care (Mellegård, Grossi & Soares, 2001). The patients with fibromyalgia were found to be able to achieve less frequent pain through so called pain behaviours (relaxation, painkillers, walks, hot baths or showers or electric pads). This finding shows similarities with a documented pattern of patients later recovering from fibromyalgia during the stage of fibromyalgia benefiting from alternative treatments in the form of substantial gaps in pain. These gaps were ascribed to techniques like massage, acupuncture, relaxation, chi-gong or zone-therapy (Wentz, Lindberg & Hallberg, 2004 b). Further, women who had recovered from fibromyalgia secured a recovery on parole through careful management of health needs as pacing of activity (Wentz, Lindberg & Hallberg, 2004b). Also Mengshoel and Heggen (2004) related summoned up statements from women who had recovered from fibromyalgia in terms of long-lasting return of symptoms presently being counteracted through the women listening to pain signals from their bodies as indicators of current level of life stress. According to these women they achieved remission of cropping up symptoms within a few days through slowing down. A dynamic, suggestible from the descriptions of the related studies, is that psychological (conscious and cautious) handling of everyday stressors, including physical load, has replaced the biological



adaption - the allostasis of the organism. Allostasis is defined as the homeostasis or the stability of the organism getting secured through the ability of the organism to adjust to fluctuations of load or challenges (McEwen, 2003). An example of this could be a hypothesised biological incapacity of the individual to get a move on or stand a temporary increase in psychological tension. The loss of biological capacity to accelerate or correspond to psychological strain is replaced with cautious pacing of activity and otherwise ways of living. Such a suggestion presupposes that the pain sensation in fibromyalgia plays a role of indicator of 'overdraft' regarding the altered and diminished allostatic ability in present or former sufferers from fibromyalgia.

The present results (as from SF-36), documenting a substantial level of psychological load during the state of fibromyalgia, might in the suggested context of diminished allostatic capacity have implications for the maintenance of generalised pain. The suggestion that allostatic mechanisms are substituted by downright psychological regulation in former patients, in order to secure absence of symptoms, implicates that in patients maintaining the pain, psychological tensions or physical load might be insufficiently regulated. It could be suggested that unregulated or not handled psychological tensions, or physical load, constitutes an overdraft regarding allostasis manifesting itself by a signal -fibromyalgia pain.

Pain in fibromyalgia could also be considered from the angle of a psychophysical protective reaction (alteration of perception) of allowing the psyche to be flooded with bodily sensations related by Dahlgren (2003). In the psychodynamic tradition this protective reaction is not regarded as a psychological defence mechanism but as a developmental precursor to perceptual defences (e.g. denial and repression). The related increase in perceptual sensitivity constitutes a barrier against mental overload including the separation of the infant from the mother that is experienced as mutilation of the body (Dahlgren, 2003). In favour of a similar mechanism being effective in fibromyalgia pain could speak the dynamics of mental load (study 1 and 2) a documented psychophysical alteration (Harju, 2001) and a connection between mutilation anxiety and fibromyalgia (Malt & Ursin, 2004). Further, the results of this thesis on an insufficient sense of self, lack of 'auxiliary ego' functioning and employment of perceptual defences parallel the psychological pattern related by Dahlgren (2003).

### *Repressor patterns*

The IMS-scale places the defence of over activity in a context of self-neglect, self-disinterest, perceptual defences (including activity based

dissociation) and susceptibility to the psychological content of others, corresponding to an avoidant defence-style – repressor coping. Repressor coping marked by avoidant defences is according to Blatt (1995) also connected to interpersonal relatedness at the expense of definition of the self. The repressor coping style was identified in the present results through e. g. the perceptual defence of ignoring pain signals, mirrored by the most discrimination items of all in study 3.” I had difficulties to understand and accept that I got temporary aches/pain sometimes”. This and similar items correspond to a repressor coping pattern reported by Schwartz (1995) of a notably heightened pain threshold when compared to non-repressor controls. This property of ‘repressors’ of an increased ability to stand pain, also identified in the result from the present studies, contradict suggestions often made on a connection between fibromyalgia and somatisation as by Sayar, Gulec and Topbas (2004) aiming at over report regarding somatic symptoms. Instead of assuming that over report is the cause of frequent report on divers somatic symptoms (Poyhia, Da Costa & Fitzcharles, 2001; Waylonis & Heck, 1992) by patients with fibromyalgia a pattern of heightened physiological reactivity tied to “repressor-coping” defence-style (Weinberger, 1995) could be considered.

An aspect of the results from the present studies could be descriptions of inflexible defence measures related to ‘life-stress’. In this context it is noteworthy that during experimental conditions of stressful tasks, it was suggested (Weinberger, 1995), that repressor coping, was related to “inflexible adherence to a predetermined self-image” rather than adaptability. Another example of an ‘inflexible adherence to a predetermined self-image’ could be the result from SASB (study 4) indicating an orientation towards control in women with fibromyalgia when compared to women with organically explained long-lasting pain. It could be suggested that a women suffering from fibromyalgia did not allow themselves to decrease demands on themselves thereby not reaching unanimity with their physical condition, as perhaps did the comparison group with long-lasting pain. This incongruence of psychological functioning might contribute to the maintenance of a high level of mental (and physical) load during the stage of fibromyalgia thereby preventing remission of symptoms. Another meaning of control as identified employing the SASB might be “to control” (the notion of) external and internal reality through perceptual defences –repressor coping.

The use of dissociation, in this context reinforced by intense activity patterns, besides signalling weakness regarding psychological functioning

also in itself constitutes a major threat regarding vital exhaustion due to absence of pacing of activity, difficulties adapting to older age etc. These two aspects of pre morbid hyperactivity and hyperactivity during the state of fibromyalgia might interact and produce a condition where exhaustion of the soma undermines an already fragile mental apparatus whose functioning is to an extreme extent relying upon the vitality of the organism as a whole.

### *Implications for treatment and prevention*

Based on the results from study 1 and 2, a decrease in mental load aiming at stabilisation of psychological functioning of the individual comes forward as a measure needed to be considered in treatment of fibromyalgia. Hence, the subjective situation of the individual (not forgetting the latent level) needs to be thoroughly assessed through clinical psychological exploration. Personally relevant stressors of the individual influencing health, including exhausting hyperactivity, need to be accounted for in both prevention and rehabilitation. A connection between mental load and symptoms in fibromyalgia might also be illustrated by Scott (1999) reporting that levels of complaints/symptoms were related to everyday hassles, anxiety and depression. These factors overshadowed the coping strategy of avoidance in predicting levels of complaints. According to Herman (1992) a foundation for the recovery from trauma (as child abuse) is establishment of conditions of safety as a sense of power or control. Based on the results from study 2, a good relationship with a good doctor dealing with issues as diagnosis, sleep deprivation, workload or over activity, seems motivated in patients with fibromyalgia. This way the necessary development of the function of an auxiliary ego could also be promoted. Regarding the importance of support from health care, Scott (1999) related that, patients with fibromyalgia, who experienced that they had been taken seriously, reported a lower level of complaints than patients that reported not having been taken seriously by health care. A need for support from the family and significant others, on behalf of the group of patients, could be dealt with through high quality education supplied by “the good doctor”. An influence from support from significant others on remission of symptoms, is suggestible from study 2 and from a description of a successful six-month rehabilitation programme (Bennet, Burckhardt, Clark, O’Reilly, Wiens & Cambell, 1996) by which significant others were summoned to group sessions and also trained to assist in daily stretching of muscles. In line with this suggestion, Montoya, Larbig, Braun, Preissl and Birbaumer (2004) found, through employment of experimental design, that brain activation and subjective ratings regarding painful stimulation decreased (as did pain sensitivity) in the presence of a significant other in patients with fibromyalgia but not in patients with migraine. These results were discussed in terms of the

presence of a supportive other diminishing the appraisal of threat or buffering the neuroendocrine and cardiovascular reactions to stress.

Based on the results from study 2, but also on the results from Mellegård Grossi and Soares (2001) showing that patients with fibromyalgia achieved less frequent pain through so called pain behaviours (relaxation, painkillers, walks, hot baths or showers or electric pads), different treatment modalities such as relaxation need also to be offered and tried out in order for the individual to experience some control, relief and hope. The development and use of auxiliary ego functions could also in this context be promoted through the individual patient being supplied with humbly formulated suggestions in relation to techniques also paralleled with shared increased awareness regarding the context of less pain or gaps in pain. This insight being an important integrated part in individualised rehabilitation heading at decrease in symptoms. Individualisation in this context need also be expressed through the patient herself/himself being asked what she or he thinks should be the best measure by which to begin the journey of rehabilitation with. Personal growth including development of affect tolerance and auxiliary ego functions could be facilitated through group therapy and/or individual psychotherapy. This need for verbalizing the issues of life might find its parallel in the view of Herman (1992) that unmanageable experiences are dealt with through the action of 'telling a story'. In the service of the individual having to face the challenge of loss of full health, the necessity creating a climate in health care, facilitating the process of crisis and mourning, stands forth based on the present results.

**Conclusion:** In relation to development of fibromyalgia, subgroups regarding the meaning of having an *unprotected self* could be identified. In the temporal processes described in study 1 and 2 not all participants were overactive before onset of symptoms. Their 'unprotectedness' or main life stress could be more marked by other qualities as *difficulties handling affects and stimulation* or *difficulties in problem solving and mourning*. A dominating pattern constituting the largest subgroup regarding *compensating strategies* related to *unprotected self* or *strong but not enough to be weak* in study 1 and 2, and supported by study 3 and 4, was employment of over activity. Regarding this 'largest' subgroup, the individual in order to gain remission of symptoms, has to solve the conflict between not being able to be overactive any more and her/his need to employ this kind of defence structure. This conflict seems to have been solved, in the service of lowering the level of strain, in the case of recovery. 'This solving of conflict' could thereby also model rehabilitating measures. In other words psychological patterns of disregulation could be hypothesised to cause but also later in the process parallel alterations in the somatic homeostatic functions of the body.

Recovery seems to mean replacement of biological mechanisms or automations with conscious minute control as pacing of work. Also in the case of 'unprotected' functioning not being paired with over activity the vulnerability itself need to be worked through or compensated for in order to decrease the 'going on' of mental load.

## References

- Ahles, T. A., Yunus, M. B., Gaulier, B., Riley, S. D., & Masi, A. T. (1985). The use of contemporary MMPI norms in the study of chronic pain patients. *Pain, 24*, 159-163.
- Almqvist, K., Jansson, S., & Broberg, A. (2002). *Barn som har bevittnat våld mot mamma. En undersökning av kvinnor och barn som vistas på kvinnojourer i Göteborg.* [Children who have witnessed violence against mummy. A study of women and children staying at women's shelters in Göteborg.] Rep. No 2. Karlstad, Sweden: University of Karlstad, Center of Public Health studies.
- Amir, M., Kaplan, Z., Neumann, L., Sharabani, R., Shani, N., & Buskila, D. (1997). Posttraumatic stress disorder, tenderness and fibromyalgia. *Journal of Psychosomatic Research, 42*(6), 607-13.
- Anch, A.M., Lue, F.A., McLean, A. W., & Moldofsky, H. (1991). Sleep physiology a psychological aspects of the fibrositis (fibromyalgia) syndrome. *Canadian Journal of Psychology, 45*, 179-184.
- Andersson A. L., Hallborg, A. (1986). Vägledning i perceptgenetisk försvarsdiagnostik med DMTm enligt Anderssons modell. Sju kliniska fall. (Psykologi i tillämpning. [Guide to perceptual genetic diagnostics of defence using the DMTm according to the model of Andersson. Seven clinical cases.] Forskningsrapport från Institutionen för tillämpad psykologi. No. 1. Lund, Sweden: Lund University.
- Arver, S. (2001). Ung med tung social problematik. [Young with a severe social complex of problems.] *Psykologtidningen, 2*, 10-11.
- Barbour, C. (2000). Use of complementary and alternative treatments by individuals with fibromyalgia syndrome. *Journal of the American academy of nurse practitioners, 122* (8), 311-316.
- Benjamin, L. S. (1974). Structural analysis of social behavior. *Psychological Review, 81*(5), 392-425.
- Bengtsson, M., Bengtsson, A., Jorfeldt, L. (1989). Diagnostic blockade in primary fibromyalgia at rest and during exercise. *Pain, 39*(2), 171-180.
- Bengtsson, A., Bäckman, A., Lindblom, B., & Skog, T. (1994). Long term follow-up of fibromyalgia patients: Clinical symptoms, muscular function, laboratory tests -an eight year comparison study. *Journal of Musculoskeletal Pain, 2*(2), 67-80.
- Bengtsson, A., Henriksson, K. G., Jorfeldt, L., Kågedal, B., Lennmarken, C., & Lindström, F. (1986). Primary fibromyalgia. A clinical and laboratory study of 55 patients. *Scandinavian Journal of Rheumatology, 15*, 330-347.

- Bengtsson, A., & Henriksson, K.G. (1996). Fibromyalgiens orsaker både perifera och centrala.[The causes of fibromyalgia are both central and periphery] *Läkartidningen*, 93 (3), 161-163.
- Bennett, R. M., Burckhardt, C. S., Clark, S.R., O'Reilly, C. A., Wiens, A.N., & Cambell, S.M. (1996). Group treatment in fibromyalgia: A 6 month outpatient program. *The Journal of Rheumatology*, 23(3), 521-528..
- Bodlund, O., Armelius, K. (1994). Self image and personality traits in gender identity disorders: an empirical study. *Journal of sex and marital therapy*, 20, 303-317.
- Blatt, S. J. (1995). Interpersonal relatedness and self definition. In Singer, J. L. (Ed.) *Repression and Dissociation. Implications for personality theory, psychopathology, and health.* (pp. 299-336). Chicago:University of Chicago Press.
- Breslau, N. (2002). Gender differences in trauma a posttraumatic stress disorder. *Journal of Gender specific Medicine*, 5 (1), 34-40.
- Brewin, C. R., Andrews, B., & Gotlieb, I. H. (1993). Psychopathology and early experiences. A reappraisal of retrospective reports. *Psychological Bulletin*, 113(1) 82-93.
- Briere, J. N. (1992). *Child abuse and trauma*. Newbury Park, London, New Dehli: Sage Publications.
- Brosschot, J.F., & Aarsse, H. R. (2001). Restricted emotional processing and somatic attribution in fibromyalgia. *International Journal of Psychiatry and Medicine*, 31(2), 127-146.
- Buckelew, S.P., Murray, S.E., Hewett, J.E., Johnson J., & Huyser, B. (1995). Self-efficacy, pain, and physical activity among fibromyalgia subjects. *Arthritis Care Research*; 8(1), 43-50.
- Buskila, D., Neumann, L., Hersman, E., Gedalia, A., Press, J., & Sukenik, S. (1995). Fibromyalgia in Children -An Outcome Study. *The Journal of Rheumatology*, 22(3), 525-528.
- Bäckman, E., Bengtsson, A., Lennmarken, C., & Henriksson, K. G. (1988). Skeletal muscle function in primary fibromyalgia. Effects of regional sympathetic blockade with guanethidine. *Acta Neurologica Scandinavica*, 77 (3), 187-191.
- Cohen, H., Neumann, L., Haiman, Y., Matar, M. A., Press, J., & Buskila, D. (2002). Prevalence of post-traumatic stress disorder in fibromyalgia patients: Overlapping syndromes or posttraumatic fibromyalgia syndrome. *Seminars in Arthritis and Rheumatism*, 32 (1), 38-50.
- Christiansson, S-Å. (2002). *Traumatiska minnen*. [Traumatic memories.] Stockholm: Natur och Kultur.
- Dahlgren, A. (2003). Autism från ett psykoanalytiskt perspektiv. [Autism from a psychoanalytic perspective.] *Psykisk Hälsa*, 2(44), 109-122.

- Dailey, P. A., Bishop, G. D., Russell, I. J., Fletcher, E. M. (1990) Psychological stress and the fibrositis/fibromyalgia syndrome. *Journal of Rheumatology*, 17(10), 1380-1385.
- Davis, M. C., Zautra, A. J., Reich, J. W. (2001) Vulnerability to stress among women in chronic pain from fibromyalgia and osteoarthritis. *Annals of Behavioural Medicine*, 23 (3), 215-226.
- Ekselius, L., Bentsson, A., & von Knorring, L. (1998). Personality traits as determined by means of the Karolinska Scales of Personality in patients with fibromyalgia. *Journal of Musculoskeletal Pain*, 6 (2), 35-49.
- Elert, J. E., Rantapää-Dahlquist, S. B., Henriksson-Larsén, K., Lorentzon, R., & Gerdlé, B. (1992). Muscle performance, electromyography and fibre type compositions in fibromyalgia and work-related myalgia. *Scandinavian Journal of Rheumatology*, 21 (19), 28-34.
- Ellertsen, B., Vaeröy, H., Endresen, I., & Förre, Ö. (1990). MMPI in fibromyalgia and non specific myalgia. Vaeröy, H. ed. Pain, Neuropeptides, Sympathetic responses and personality factors in patients with Fibromyalgia (fibrosites syndrome). Unpublished doctoral dissertation, Oslo University, Oslo.
- Eysenck, H. J. (1993). Prediction of cancer and coronary heart disease mortality by means of a personality inventory: results of a 15-year follow-up study. *Psychological Report*, 72(2), 499-516.
- Faroqui, A., & Gibson, T. (1998). Prevalence of the major rheumatic disorders in the adult population in Pakistan. *British Journal of Rheumatology*, 37(5), 491-495.
- Felson D.T., & Goldenberg D.L. (1986). The natural history of fibromyalgia. *Arthritis and Rheumatism*, 29(12), 1522-6.
- Gagliese, & Katz, J. (2000). Medically unexplained pain is not caused by psychopathology. *Pain Research & Management*, 5, 251-257.
- Glaser, B.G., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Glaser, B. (2002). Grounded Theory and gender relevance. *Health Care for Women International* 23(8), 786-793. Goldenberg, D. L. (1993). Do infections trigger fibromyalgia? *Arthritis and Rheumatism*, 36, 1489-1492.
- Grace, G M., Nielson, W.R., Hopkins, M., & Berg, M.A. (1999). Concentration and memory deficits in patients with fibromyalgia syndrome. *Journal of Clinical Experimental Neuropsychology*, 21 (4), 477-87.
- Granges, G., Zilko, P., & Littlejohn, G O. (1994). Fibromyalgia syndrome: Assessment of severity of the condition 2 years after diagnosis. *The Journal of Rheumatology*, 21(3), 523-529.
- Greenfield, S., Fitzcharles, M. A., & Esdale, J. M. (1992). Reactive fibromyalgia syndrome. *Arthritis and Rheumatism*, 35(6) 678-681.
- Griep, E.N., Boersma, J.W., & de Kloet, E.R. (1993). Altered reactivity of the hypothalamic-pituitary-adrenal axis in the primary fibromyalgia syndrome. *Journal of Rheumatology*, 20, 469-74.

- Hallberg L. R-M., & Carlsson, S.G. (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Sciences*, 12(2), 95-103.
- Hallberg, L. R-M., & Carlsson S.G. (1998). Anxiety and coping in patients with chronic work-related muscular pain and patients with fibromyalgia. *European Journal of Pain*, 2, 309-319.
- Harju, E-L. (2001). *Quantitative and qualitative analysis of touch, cold and warmth in health, neuropathic pain and fibromyalgia*. Unpublished doctoral dissertation, Stockholm University & Karolinska Institutet, Stockholm, Sweden.
- Henningsson, M., Armelius, B-Å, & Erdberg, P. (2001) PLS model building: A multivariate approach to personality test data. *Scandinavian Journal of Psychology*, 42, 309-409.
- Henriksson, C. M. (1995). *Living with fibromyalgia. A study of the consequences for daily activities* Unpublished doctoral dissertation, Linköping University, Linköping, Sweden.
- Henriksson, K. G. (2002). Is fibromyalgia a central pain state? *Journal of Musculoskeletal Pain*, 10(½), 45-57.
- Henriksson, C., Carlsberg, U., Kjällman, M., Lundberg, G., & Henriksson, K. G. (2004). Evaluation of four outpatient educational programmes for patients with longstanding fibromyalgia. *Journal of Rehabilitation Medicine*, 36(5), 211-9.
- Herman, J. L. (1992). *Trauma and recovery*. New York: BasicBooks.
- Jacobsson, C. (1989). Fibromyalgi, smärta och försvar. [Fibromyalgia, pain and defence.] (Psykologi i tillämpning No. 3.) Forskningsrapport från Institutionen för tillämpad psykologi. No. 1. Lund, Sweden: Lund University.
- Jacobsson, L., Lindgade, F., & Manthorpe, R. (1989). The commonest complaints of over six weeks' duration in a twelve-month period in a defined Swedish population. Prevalences and relationships. *Scandinavian Journal of Rheumatology*, 18 (6), 353-360.
- Johnson, M. (1997). *On the dynamics of self esteem. Empirical validation of Basic self-esteem and Earning self-esteem*. Unpublished doctoral dissertation, Stockholm University, Stockholm, Sweden.
- Keel, P.J., Bodoky, C., Urs, G., & Müller, W. (1998). Comparison of integrated group therapy and group relaxation training for fibromyalgia. *The clinical journal of pain*, 14, 232-238.
- Khan, M. M. R. (1963). The concept of cumulative trauma. *Psychoanalytic study of the child*, 18, 286-306.
- Kwiattek, R., Branden, L. Tedman, R., Jarret, R., Chew, J., Rowe, C. & Pile, K. (2000). Regional cerebral blood flow in fibromyalgia: single photon-emission computed tomography incidence of reduction in the pontine tegmentum and thalami. *Arthritis and Rheumatism*, 43, 2822-2833.



- Landrö, N I., & Winnem, M. F. (1987). Psychodiagnostic evaluation of patients with myofacial pain syndrome. [Abstract]. *Pain*, Suppl. No. 4, S 419.
- Ledingham, J., Doherty, S., & Doherty, M. (1993). Primary fibromyalgia syndrome – an outcome study. *British Journal of Rheumatology*, 32, 139-142.
- Lindell, L., Bergman, S., Petersson, I. F., & Herrström, P. (2000). Prevalence of fibromyalgia and chronic widespread pain. *Scandinavian Journal of Primary health Care*, 18(3), 149-153.
- Malterud, K. (2001). Qualitative research: standards, challenge, and guidelines. *Lancet*, 358, 483-488.
- Malt, E. A., & Ursin H. (2003). Mutilation anxiety differs among females with fibromyalgia and functional dyspepsia and population controls. *Journal of Psychosomatic Research*, 54 (6), 523-31.
- Mannerkorpi, K., Kroksmark, T., & Ekdahl, C. (1999). How patients with fibromyalgia experience their symptoms in everyday life. *Physiotherapy Research International*, 4(2), 110-122.
- Martinez-Lavin, M., Hermosillo, A. G, Rosas, M., & Soto, M. E. (1998). Circadian studies of autonomous nervous balance in patients with fibromyalgia. A heart rate variability analysis. *Arthritis and Rheumatism*, 42, 1966-1971.
- Martinez-Lavin, M., Koo, M., Meza, S., Martin del Campo, A. M. Hermosillo, A. G, Pineda, C., Amigo, M. C., Nava, A., & Drucker-Collins, R. (1999). Simultaneously studies of heart rate variability in polysomnography in patients with fibromyalgia. *Arthritis and Rheumatism*, 42, S 344.
- Martinez-Lavin, M. (2001). Is fibromyalgia a generalized reflex sympathetic dystrophy? *Clinical and Experimental Rheumatology*, 19, 1-3.
- Martinez-Lavin, M. (2002). The autonomic nervous system and fibromyalgia. *Journal of Musculoskeletal Pain*, 10(½), 221-228.
- McEwen B. S., Wingfield J. C. (2003). The concept of allostasis in biology and biomedicine. *Hormones and Behaviour*, 43(1), 2-15.
- Melzack, R., & Casey, K. L. (1968). Sensory, motivational and central control determinants of pain: a new conceptual model. In D. Kenshalo, D. (Ed.). *The Skin Senses*. Springfield, Illinois.
- Mengshoel, AM., Heggen K.(2004). Recovery from fibromyalgia - previous patients' own experiences. *Disability and Rehabilitation*, 26(1),46-53.
- Mellegård, M. Grossi, G., Soares, J. J. F. (2001). A comparative study of coping among women with fibromyalgia, neck/shoulder and back pain. *International Journal of Behavioural Medicine*, 8(2), 103-15.
- Moldofsky, H., & Scarsbrick, P. (1976). Induction of neurasthenic musculoskeletal pain syndrome by selective sleep stage deprivation. *Psychosomatic Medicine*, 38 (1), 35-44.
- Moldofsky, H., Scarsbrick, P., England, R., & Smythe, H. (1975). Musculoskeletal symptoms and non-REM sleep disturbance in patients with 'fibrositis syndrome' and healthy controls. *Psychosomatic Medicine*, 37 (4), 341-351.

- Montoya, P., Larbig, W., Braun, C., Preissl, H., & Birbaumer N. (2004). Influence of social support and emotional context on pain processing and magnetic brain responses in fibromyalgia. *Arthritis and Rheumatism*, 50(12), 4035-44.
- Mäkelä, M., & Heliövaara, M. (1991). Prevalence of primary fibromyalgia in the Finnish population. *British medical Journal*, 303(6796), 216-219.
- Norlander, T., Bood, S-Å., & Archer, T. (2002). Performance during stress: Affective personality, age, and regularity of physical exercise. *Social behaviour and Personality*, 30(5), 495-508.
- Nunnally, J. C., & Bernstein, I. H. (1994) *Psychometric theory*. New York: McGraw-Hill, Inc.
- Page, T. F. (1998). Linkages between children's narrative representations of families and social competence in child-care-settings. (Doctoral Dissertation, University of Wisconsin –Madison, 1998). *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 59 (5A): 1777.
- Page, T. F. (2001). Attachment themes in the family narratives of pre-school children: A Qualitative analysis. *Child and Adolescent Social Work Journal*, 18,(5), 353-375.
- Payne, T. C., Leavitt, F., Garron, D. C., Katz, R. S., Golden, H. E., & Glickman, P. B. (1982). Fibrositis and psychological disturbance. *Arthritis and Rheumatism*, 25, 213-217.
- Perry, F., Heller, P. H., & Levine, J. D. (1988). Differing correlations between pain measures in syndromes with or without explicable organic pathology. *Pain*, 34, 185-189.
- Poyhia, R., Da Costa, D., & Fitzcharles, M.A. (2001). Previous pain experience in women with fibromyalgia and inflammatory arthritis and nonpainful controls. *Journal of Rheumatology*, 28(8), 1888-91.
- Romano, T. J. (1992). Coexistence of fibromyalgia syndrome (FS) and systemic lupus erythematosus. [Abstract] *Scandinavian Journal of Rheumatology*, 21(suppl. 94), 12.
- Romano, T. J. (1992). Incidence of fibromyalgia syndrome (FS) in rheumatoid arthritis (RA) patients in general Rheumatology practice. systemic lupus erythematosus. [Abstract] *Scandinavian Journal of Rheumatology*, 21(suppl. 94), 11.
- Romano, T. J. (1992). Presence of fibromyalgia syndrome (FS) in osteoarthritis (OA) patients. [Abstract] *Scandinavian Journal of Rheumatology*, 21(suppl. 94), 11.
- Rush P. J., & Ameis A. Trauma and fibromyalgia: does the punishment fit the crime? *Journal of Rheumatology*, 22(2), 372-4.
- Saskin, P., Moldofsky, H., & Lue, F.A. (1986). Sleep and posttraumatic rheumatic pain modulation disorder (fibrositis syndrome). *Psychosomatic Medicine*, 48 (5), 319-323.

- Sayar, K., Gulec, H., & Topbas, M. (2004). Alexithymia and anger in women with fibromyalgia syndrome. *Clinical Rheumatology*, 23(5), 441-448.
- Scamell, S. (2001). Illness as a transformative gift in people with fibromyalgia. *Dissertation Abstracts International*, 62, 2-B. California Institute of Integral Studies, US.
- Scott, B. (1999). Coping. Fibromyalgi. [Coping. Fibromyalgia.] *Rehabilitering*, 2, 10-11.
- Schacter, D.L. (1999). The seven sins of memory. Insights from psychology and cognitive neuroscience. *American Psychology*, 54(3), 182-203.
- Schwartz, G. E. (1995) Psychobiology of Repression and Health. In Singer, J. L. (Ed.) *Repression and Dissociation. Implications for personality theory, psychopathology, and health.* (pp. 405-434). Chicago:University of Chicago Press.
- Seedat, S., & Stein, M. (2001). Posttraumatic stress disorder: A review of recent findings. *Current Psychiatry Reports*, 3(4), 288-294.
- Shermann, J. J., Turk, D. C., & Okifuji, A. (2000). Prevalence and impact of posttraumatic stress disorder-like symptoms on patients with fibromyalgia syndrome. *The clinical Journal of Pain*, 16, 127-134.
- Simms, R. W., Zerbini, C. A., Ferrante, N., Anthony, J., Felson, D. T., & Craven, D. E. (1992). Fibromyalgia in patients infected with human immunodeficiency virus. *American Journal of Medicine*, 92(4), 368-374.
- Sletvold, H., Stiles, T. C., & Landrö, N. (1995). Information processing in primary fibromyalgia, major depression and healthy controls. *Journal of Rheumatology*, 22(1), 137-142.
- Strauss, A. & Corbin, J. (1996). *Basics of Qualitative research. Techniques and procedures for developing grounded theory.* California: Sage Publications.
- Söderberg, S. (1999). *Women's experience of living with fibromyalgia: Struggling for dignity.* Unpublished doctoral dissertation, Umeå University, Umeå, Sweden.
- Taylor, G. J. (1992) Psychoanalysis and psychosomatics: a new synthesis. *Journal of the Academy of Psychoanalysis*, 20 (2), 251-275.
- Taylor, S. E., Klein, L. C., Lewis, B. P., Gruenwald, T. L., Gurung, R. A. & Updegraff, J. A. (2000). Bio-behavioural responses to stress in females: tend-and befriend not fight-and-flight. *Psychological Review*, 107(3), 411-429.
- The Iowa Gulf Study Group (1997). Self reported illness and health status among Gulf War Veterans. A population based study. *JAMA*, 277 (3), 238-245.
- Toskala, A., Kangasniemi, K., Vasarinen, A., & Nurmikko, T. (1993). Pain and the symbolic function. *Psychiatria Fenneca*, 22, 101-102.
- Tuzun, E. H., Albayrak, G. A. L., Eker, L., Suzay, S., & Daskarpan, A. (2004). A comparison study of quality of life in women with fibromyalgia and

- myofascial pain syndrome. *Disability and Rehabilitation*, 26 (4), 198-202.
- Uveges J.M., Parker J.C., Smarr K.L., McGowan J.F., Lyon M.G., & Irvin W.S. (1990). Psychological symptoms in primary fibromyalgia syndrome: relationship to pain, life stress, and sleep disturbance. *Arthritis and Rheumatism*, 33(8), 1279-83.
- Walker, E.A., Keegan, D., Gardner, G., Sullivan, M., Bernstein, D., & Katon, W.J. (1997). Psychosocial factors in fibromyalgia compared with rheumatoid arthritis: II. Sexual, physical, and emotional abuse and neglect. *Psychosomatic Medicine*, 59(6), 572-7.
- Van Denderen, J.C., Boersma, J.W., Zeinstra, P., Hollander, A.P., & van Neerbos, B. R.(1992). Physiological effects of exhaustive physical exercise in primary fibromyalgia syndrome (PFS): is PFS a disorder of neuroendocrine reactivity? *Scandinavian Journal of Rheumatology*, 21(1), 35-7.
- Van Houdenhove, B., Neerinckx, E., Lysens, R., Vertommen, H., Van Houdenhove, L., & Onghena P. (2001). Victimization in chronic fatigue syndrome and fibromyalgia in tertiary care: a controlled study on prevalence and characteristics. *Psychosomatics*, 42(1), 21-8.
- Van Houdenhove, B., Neerinckx E., Onghena, P., Lysens, R., & Vertommen, H. (2001). Premorbid "overactive" life-style in chronic fatigue syndrome and fibromyalgia. An etiological factor or proof of good citizenship? *Journal of Psychosomatic Research*, 51(4), 571-6.
- Waylonis, G. W., & Heck, W. (1992). Fibromyalgia syndrome. New associations. *American Journal of Physical medicine and Rehabilitation*, 71(6), 345-347.
- Weinberger, D. A. (1995). The construct validity of the repressor coping style. In Singer, J. L. (Ed.) *Repression and Dissociation. Implications for personality theory, psychopathology, and health*. (pp. 337-386). Chicago:University of Chicago Press.
- Wentz, K. A. H., Lindberg, C., & Hallberg, L. R-M. (2004a). Psychological functioning in women with fibromyalgia. A grounded theory study. *Health Care for Women International*, 25(8),702-729.
- Wentz, K. A. H., Lindberg, C., & Hallberg, L. R-M. (2004b). *On parole –recovery from fibromyalgia in women: a grounded theory study*. Manuscript submitted for publication.
- White, K. P., & Harth, M. (2001). Classification, Epidemiology and natural history of fibromyalgia. *Current Pain and Headaches Reports*, 5, 320-329.
- White, K. P., Nielson, W. R., Harth, M., Ostbye, T., & Speechley, M. (2002). Does the label “Fibromyalgia” alter health status, function and health service utilization? A prospective within-group comparison in a community cohort of adults with chronic widespread pain. *Arthritis & Rheumatism*, 47 (3), 260-265.
- Visuri, T., Lindholm, H., Lindqvist, A., Dahlström, S. & Viljanen, A. (1992). Cardiovascular functional disorder in primary fibromyalgia: non-invasive study in 17 young men. *Arthritis Care and Research*, 5(4), 210-15.

- Wolfe, F., Catley, M. A., Katon, S. M., Amos, S. P., Hoffman, R. G. & Young, D. Y. (1984). Psychological functioning in primary fibrositis and fibrositis associated with rheumatoid arthritis. *Journal of Rheumatology*, 11 (4), 500-506.
- Wolfe, F., Smythe, H. A., Yunus, M. B., Bennet, R. M., Bombardier, C., & Godenberg, D. L. (1990). The American College of Rheumatology 1990 criteria for the classification of fibromyalgia. *Arthritis and Rheumatism*, 33,(2), 160-172.
- Wolfe, F., Ross, K., Anderson, J., Russel, I. J. & Herbert, L. (1995). The prevalence and characteristics of fibromyalgia in the general population. *Arthritis & Rheumatism*, 38, 19-28.