STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH
180

Merja Sallinen

Women's narratives on fibromyalgia, functioning and life events

JYVÄSKYLÄN YLIOPISTO

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH 180

Merja Sallinen

Women's narratives on fibromyalgia, functioning and life events

Esitetään Jyväskylän yliopiston liikunta- ja terveystieteiden tiedekunnan suostumuksella
julkisesti tarkastettavaksi yliopiston Agora-rakennuksen auditoriossa 2
huhtikuun 27. päivänä 2012 kello 12.

Academic dissertation to be publicly discussed, by permission of
the Faculty of Sport and Health Sciences of the University of Jyväskylä,
in building Agora, auditorium 2, on April 27, 2012 at 12 o'clock noon.

UNIVERSITY OF JYVÄSKYLÄ

JYVÄSKYLÄ 2012

Women's narratives on fibromyalgia, functioning and life events

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH 180

Merja Sallinen

Women's narratives on fibromyalgia, functioning and life events

UNIVERSITY OF JYVÄSKYLÄ

JYVÄSKYLÄ 2012

Editors
Ina Tarkka
Department of Health Sciences, University of Jyväskylä
Pekka Olsbo, Ville Korkiakangas
Publishing Unit, University Library of Jyväskylä

Cover picture: Johanna Kukkola

URN:ISBN:978-951-39-4696-8
ISBN 978-951-39-4696-8 (PDF)

ISBN 978-951-39-4695-1 (nid.)
ISSN 0356-1070

Jyväskylä University Printing House, Jyväskylä 2012

ABSTRACT

Sallinen, Merja
Women's narratives on fibromyalgia, functioning and life events
Jyväskylä: University of Jyväskylä, 2012, 68 p.
Studies in Sport, Physical Education and Health
ISSN 0356-1070; 180)
ISBN 978-951-39-4695-1 (nid.)
ISBN 978-951-39-4696-8 (PDF)
Finnish summary
Diss.

In this study, fibromyalgia was approached from the perspective of women with a long illness history. The purpose of the study was to explore how they described their experiences of functioning, work ability and rehabilitation and how they expressed and interpreted their life events and illness experiences as a life story. The data were collected through narrative interviews of twenty middle-aged women, who had participated in fibromyalgia-specific rehabilitation courses at Rheumatism Foundation Hospital in 1999-2001. A stepwise narrative analysis was conducted to elucidate what was the content of the life stories, and how the life stories were told. The results indicated that functioning and work ability of the participants had deteriorated substantially over the past years. Work ability was described as confusion, as coping with fluctuating symptoms, as being in-between and as falling over the edge of exhaustion. Fatigue was perceived as a transient, extreme and intensive experience, which caused major disability and distress, and which had consequences on every aspect of life. For many women the rehabilitation course and encounters with peers appeared to be a significant turning point after struggling with uncertainty and negative attitudes of colleagues and health care professionals for years. Peer support was described in terms of permission to talk, need for experiential knowledge, reciprocity and self-evaluation through comparison. Four different patterns of storylines were identified in the analysis process; narratives of mundane life, cumulative life and broken life and a counter-narrative. In conclusion, fibromyalgia appeared to have a substantial negative impact on work ability and functioning in patients with a long illness history. In order to plan and implement more effective and more individualized rehabilitation interventions for these patients in the future, it is important to acknowledge the diversity of life events and illness experiences experienced by persons with fibromyalgia.

Keywords: fibromyalgia, functioning, work ability, rehabilitation, narrative research

Author's address
Merja Sallinen, MSc, PT
Satakunta University of Applied Sciences
Maamiehenkatu 10, 28500 Pori
merja.sallinen@samk.fi

Supervisors
Liisa Peltokallio, PhD, PT
Department of Health Sciences
University of Jyväskylä
Jyväskylä, Finland

Marja Leena Kukkurainen, PhD, RN
Rheumatism Foundation Hospital, Heinola
and Finnish Association of Rheumatology Nurses,
Heinola, Finland

Reviewers
Målfried Råheim, PhD, PT,
Associate Professor in Physiotherapy
University of Bergen, Norway

Allison Hammond, PhD, OT,
Professor in Rheumatology Rehabilitation
University of Salford, United Kingdom

Opponent
Kaisa Mannerkorpi, PhD, PT,
Associate Professor in Rheumatoid Research,
University of Gothenburg/Sahlgren Academy, Sweden

ACKNOWLEDGEMENTS

As novelist Paulo Coelho writes in his famous story "How to climb mountains", the distance to the top is always greater than one thinks. However, sooner or later something that was once only a dream, a distant vision, becomes real. I wish to thank all the people who have supported me in many different ways during this dissertation project and thus helped me to climb my mountain.

I wish to address my deepest appreciation to my two supervisors PhD Marja Leena Kukkurainen and PhD Liisa Peltokallio for their dedication and skillful guidance throughout the whole process. Their warm-hearted support has helped me to climb also through the rocky parts of the path. Marja Leena's expertise in fibromyalgia has been essential in planning, implementing and reporting the study. Methodological discussions with Liisa have helped me to find new perspectives from the data and to deepen my knowledge in qualitative research. The tutorial sessions with both Marja Leena and Liisa were often filled with laughter and our discussions were seldom limited solely to research. Those moments are unforgettable!

I am grateful to my other co-writers MD Marja Mikkelsson and PhD Ulla Marie Anderberg for their valuable contribution and excellent advice in writing the original articles. Their critical comments helped me to focus on the essential and thus to find a more scientific way of writing. The official reviewers of the dissertation Professor Målfrid Råheim and Professor Allison Hammond are kindly acknowledged for their perceptive comments that helped me to finalize this thesis. Professor Kaisa Mannerkorpi agreed to be my official opponent, for which I am both proud and grateful.

Professor Ari Heinonen is acknowledged for his patience, support and advice, especially in administrative issues in the final stage of the study. Together with Professor Arja Häkkinen he has offered me several possibilities to reflect upon my research results and to discuss methodological issues in the seminars of the doctoral students in physiotherapy. Furthermore, I wish to thank my fellow students in physiotherapy and in multidisciplinary IHME – courses for fruitful conversations during the past five years. Sharing ideas and experiences with other students has made this journey less arduous.

I thank my colleagues in physiotherapy and rehabilitation education in Satakunta University of Applied Sciences for their support and encouragement during this long process. The sarcastic jokes and daily worries that we share at the coffee table every day have helped me to keep my feet firmly on the ground; thank you Viveka, Hanna, Heli, Merja, Esa, Johanna, Mari, Sirpa, Erja, Marjo, Maija, Kati and Tarja. Sirpa Saaristo has mentored me throughout my whole teaching career; especially our rehabilitation-related discussions have guided my work and research. I also wish to express my warmest thanks to Head of Education Tuula Rouhiainen-Valo and Research Director Anne Kärki for their flexibility in organizing my work duties during my doctoral studies and for offering me further challenges both in the field of education and in the area of research and development.

This dissertation project was supported by research grants by Rheumatism Foundation Hospital in Heinola and by Finnish Cultural Foundation's Regional Fund in Satakunta, which are hereby kindly acknowledged. My employer Satakunta University of Applied Sciences has supported the work by allocating working hours for this research. Without this kind of financial support the top of the mountain would remain unreached.

KIITOKSET

Tutkimustyöni ovat taloudellisesti mahdollistaneet useat tahot, joille haluan esittää lämpimät kiitokseni; Heinolassa toimineen Reumasäätiön sairaalan EVO -rahoituksen turvin sain keskittyä päätoimisena tutkijana aineiston hankintaan ja käsittelyyn sekä ensimmäisen artikkelin kirjoittamiseen. Suomen Kulttuurirahaston Satakunnan rahastosta saamieni kahden apurahan turvin olen voinut kirjoittaa kolmea artikkelia sekä väitöstutkimuksen yhteenvetoa. Satakunnan ammattikorkeakoulun antamaa jatko-opintojen aikatukea ja TKI-rahoitusta olen voinut käyttää joustavasti työn eri vaiheissa. Kiitos!

Ilman perheeni vankkumatonta tukea haaveeni jatko-opinnoista olisivat jääneet toteutumatta. Vanhempani Valma ja Esa Ihalainen ovat aina suhtautuneet kannustavasti opiskeluuni. Omalla esimerkillään he ovat osoittaneet, että kirjanoppineisuutta tärkeämpää on kuitenkin sydämensivistys. Upeat lapsemme Johanna, Jyri, Meri, Sanna, Elina ja Marleena sekä pieni lapsenlapsemme Noora muistuttavat minua päivittäin siitä, mikä elämässä on oikeasti tärkeää. Kiitos, kun saan olla äitinne ja ”mumma”! Puolisoni Tuomas on pyörittänyt perheen arkea ansiokkaasti minun keskittyessäni opiskeluuni ja työhöni toisella paikkakunnalla. Hän on jaksanut kuunnella loputtomia pohdiskelujani tutkimuksen eri vaiheissa ja kannustanut eteenpäin silloinkin, kun itse olen ollut epäilevänen työn etenemisestä. Kiitos, että olen saanut mahdollisuuden tavoitella unelmia!

Elämäjärven Mäkelässä
Huhtikuussa 2012
Merja Sallinen

LIST OF ORIGINAL ARTICLES

This doctoral thesis is based on the following four original articles, which are referred to by their Roman numerals:

I Sallinen M, Kukkurainen ML, Peltokallio L & Mikkelsson M. 2010. Women’s narratives on experiences of functioning and work ability in fibromyalgia. Musculoskeletal Care 8: 18–26.

II Sallinen M, Kukkurainen ML, Peltokallio L & Mikkelsson M. 2011. ”I’m tired of being tired”– Fatigue as experienced by women with fibromyalgia. Advances in Physiotherapy 13: 11–17.

III Sallinen M, Kukkurainen ML & Peltokallio L. 2011. Finally heard, believed and accepted –Peer support in the narratives of women with fibromyalgia. Patient Education and Counseling 85: e126 - e130.

IV Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M, Anderberg UM. 2012. Fatigue, worry and fear– Life events in the narratives of women with fibromyalgia. Health Care for Women International. In press.

ABBREVIATIONS

ACR	American College of Rheumatology
ACTH	Adrenocorticotropic hormone
CBT	Cognitive-behavioral therapy
CRH	Corticotropin releasing hormone
CWP	Chronic widespread pain
DOMS	Delayed onset of muscular soreness
EMG	Electromyography
fMRI	Functional magnetic resonance imaging
HPA axis	Hypothalamic-pituitary-adrenal axis
ICF	International Classification of Functioning Disability and Health
maxHR	Maximal heart rate
NSAID	Non-steroidal anti-inflammatory drugs
NW	Nordic walking
PTSD	Post-traumatic stress disorder
RA	Rheumatoid arthritis
RCT	Randomized controlled trial
SF-36	Medical outcome survey 36 Items
SII	Social Insurance Institute
SS-scale	Symptom severity scale
WPI	Widespread pain index
15D	15 dimension instrument of health-related quality of life

CONTENTS

1 INTRODUCTION

Fibromyalgia is a significant health problem of women in working age. It is characterized by chronic widespread pain, muscular tenderness, sleeping disorders and daytime tiredness (Arnold et al. 2008; Wolfe et al. 2010). In the current paradigm fibromyalgia is understood as the most severe end of a continuum from acute local pain, through chronic regional pain, to chronic widespread pain (Aaron & Buchwald 2003). In addition to a decrease in functioning and work ability, fibromyalgia may be associated with increased cardiovascular mortality rates and with increased use of health care services in the long run (Macfarlane et al. 2001; McBeth et al. 2009; Lindgren & Bergman 2010). Both the direct costs of treatment and the mean costs for absence from work due to fibromyalgia are substantial and comparable to those of rheumatoid arthritis and osteoarthritis (Silverman et al. 2009; Kleinman et al. 2009). In western Europe alone, up to six million people may suffer from fibromyalgia (Branco et al. 2010), and it has been calculated that the annual incremental costs of fibromyalgia may be up to €12 billion in a population of 80 million (Spaeth 2009). In Finland, this would mean annual costs of €79 million in terms of treatment costs and sickness and disability benefits caused by fibromyalgia.

From an individual point of view, fibromyalgia does not seem to make sense; the symptoms vary from one day to another, and neither the cause nor the course of the illness is known. Research suggests that in a long perspective fibromyalgia patients adapt to the symptoms, and may thus function better although the symptom level remains the same (Mengshoel & Heggen 2004; Liedberg et al. 2006). However, despite the extensive research on fibromyalgia over the past two decades, there is relatively little knowledge about the long-term impacts of fibromyalgia on functioning and how they are experienced by the patients.

This doctoral study forms part of a multimethod long-term follow-up study of patients who participated in fibromyalgia-specific rehabilitation courses in the Rheumatism Foundation Hospital in Heinola during 1999-2001. The primary purpose of the follow-up project was to explore the level of symptoms, functioning and health-related quality of life of fibromyalgia patients six to eight years after a multimodal rehabilitation course. This study brings together narrated life stories of twenty women with a long history of fibromyalgia and elucidates how the life events, rehabilitation and illness experiences are described, evaluated and re-constructed and what meanings are ascribed to these experiences.

In Chapter 2 the epidemiology, etiology and diagnostic criteria of fibromyalgia are introduced. In addition to the core signs and symptoms, earlier research on functioning and quality of life is presented and the current evidence-based treatment recommendations for fibromyalgia are introduced. In Chapter 3, the purpose of the study and the research questions are explicated. This is followed by a review on narrative methodology that was used in collection and analysis of the data (Chapter 4). Chapter 5 summarizes the findings of the study, which are presented in greater detail in the original articles. In Chapter 6, the findings and methodology are discussed and, finally, in Chapter 7, the conclusions of the study are presented.

2 FIBROMYALGIA AS A HEALTH CHALLENGE

2.1 Epidemiology

It is estimated that about 20-25% of adult population have chronic regional pain at any given time, and that 10- 11% of adults suffer from chronic widespread pain (Mäntyselkä et al. 2001; Clauw & Crofford 2003). Internationally the prevalence of fibromyalgia is estimated to be 2.2-6.6 % in the general population (Branco et al. 2010; Haviland et al. 2010), whereas in Finland the prevalence has been reported to be lower; only 1.9% (Kivimäki et al. 2007). Research suggests that perceived multiple symptoms in childhood may increase the risk of developing chronic widespread pain in later life (Jones et al. 2007; Jones et al. 2009). There is sparse research among schoolchildren or adolescents on fibromyalgia, but the results of a follow-up study by Mikkelsson et al. (2008) indicated that the prevalence of chronic widespread pain increased steadily with age, from 7% in schoolchildren aged 10–12 years to 9% at 11–13 years, and then to 15% at age 14–16 years. In comparison, Jones et al. (2003) found in a population-based study that 7.7% of the non-symptomatic schoolchildren reported new onset of widespread pain in a one-year follow-up.

The incidence of fibromyalgia seems to reach a peak in the age group of 45-55 years, after which it decreases slightly (Gallagher et al. 2004). Because full remission is rare (Papageorgiou et al. 2002; Bliddahl & Danneskiold-Samsøe 2007), the prevalence of fibromyalgia increases with age. In the age group 55-64 years, up to 8%-10 % of women may suffer from fibromyalgia (White et al. 1999). In a Finnish twin cohort study, 12-13% of the participants were categorized as ‘possible fibromyalgia patients’ but failed to fulfill the diagnostic criteria; they had a similar, albeit less severe symptom profile compared to those with a fibromyalgia diagnosis (Markkula et al. 2009). In the general population, fibromyalgia is estimated to be two to nine times more common among women than men (Gallagher et al. 2004; Branco et al. 2010). However, symptom severity may be worse in men than in women (Buskila et al. 2000).

2.2 Etiology

The etiology and pathophysiology of fibromyalgia are not fully understood, but multifactorial etiology is plausible. In contrast to rheumatoid arthritis or osteoarthritis, in fibromyalgia there is no peripheral damage or inflammation within the tissues or muscles (Yunus 2007; Ablin et al. 2008). To date, the evidence suggests that genetics, disorders of the central sensitivity system, alterations of the stress-response system, and psychosocial distress are involved in the development and maintenance of the symptoms of fibromyalgia (Diatchenko et al. 2006; Ablin et al. 2008; Dadabhoy et al. 2008).

2.2.1 Genetic factors

Arnold et al. (2004) noticed that fibromyalgia aggregates strongly in families. The researchers collected information from 533 first-degree relatives of patients with fibromyalgia and from 272 relatives of patients with rheumatoid arthritis (RA). The risk for fibromyalgia was 8.5-fold for the relatives of a fibromyalgia patient compared to those of a patient with RA. Furthermore, they noticed that tender point count and total myalgic scores (measured with a dolorimeter) were strongly associated with fibromyalgia in families, and that this association was independent of mood disorders.

In a review on genetics in fibromyalgia, the prevalence of fibromyalgia among blood relatives of fibromyalgia patients was estimated to be 26-28% (Buskila 2007). Furthermore, polymorphisms of genes in the serotoninergic, dopaminergic and cathecolaminercic systems have been suggested to play a role in the etiopathogenesis of fibromyalgia. However, these polymorphisms are not specific to fibromyalgia, and the mode of inheritance of fibromyalgia remains unknown (Buskila 2007; Ablin et al. 2008; Williams & Clauw 2009).

2.2.2 Deficits in the central sensitivity system

Studies indicate that the decreased sensory threshold that causes tenderness, hyperalgesia (i.e. increased pain in response to normally painful stimuli), and allodynia (i.e. pain in response to normally non-painful stimuli) in fibromyalgia patients may not be limited to cutaneous and muscular mechanisms, but may also occur with auditory, electronic or thermal stimuli. These findings suggest that people with fibromyalgia may have a generalized decrease in inhibitory control of noxious stimuli. In other words, the central nervous system seems to be unable to block the stimuli adequately (Geisser et al. 2007; Geisser et al. 2008; Dadabhoy et al. 2008). Similar central hypersensitization is also found in other chronic pain-related disorders, such as migraine, chronic fatigue syndrome, irritable bowel syndrome and regional soft-tissue pain syndrome (Yunus 2007).

The deficits in the pain inhibitory system may be caused by abnormalities in the concentrations of the metabolites of serotonin and other neurotransmitters in the cerebrospinal fluid, which have been found to be significantly lower in fibromyalgia patients than in healthy controls. Furthermore, increased level of substance P in the dorsal horn of the spinal cord results in amplification of nociceptive stimuli from the periphery leading to increased widespread pain. Evidence shows that in patients with fibromyalgia the level of substance P may be 3-fold higher in comparison to healthy controls. These biochemical abnormalities may also account for some other typical symptoms in fibromyalgia, such as sleep disturbances and depression (Gupta & Silman 2004; Julien et al. 2005; Dadabhoy et al. 2008; Williams & Clauw 2009).

Data corroborating the veracity of fibromyalgia patients' pain and sensitivity complaints have been collected using functional magnetic resonance imaging (fMRI). A study by Gracely et al. (2002) showed that the stimulus that was required to activate the pain processing areas in the brain was much lower in patients with fibromyalgia than in their healthy counterparts. When given the same objective stimulus intensity, the fibromyalgia patients showed greater brain activity compared to healthy controls. Furthermore, Giesecke et al. (2005) noticed that the clinical pain intensity corresponded with an increased regional cerebral blood flow in subjects with chronic widespread pain.

2.2.3 Alterations of the stress-response system

The human stress response has been closely examined for a causative role in fibromyalgia. The hypothalamic-pituitary-adrenal axis (HPA axis) along with the sympatho-adrenal system is the principal stress-response system in the human body. Acute stress prompts the hypothalamus to release corticotropin-releasing hormone (CRH) into the hypothalamic-hypophyseal portal system. Elevated level of CRH affects the release of adrenocorticotropic hormone (ACTH) from the anterior pituitary, which in turn stimulates the adrenal glands to release cortisol. Normally the elevated ACTH and cortisol levels return to normal level once the stressor has been dealt with (Gupta & Silman 2004; Dadabhoy et al. 2008). It has been suggested that the HPA axis is underactive in fibromyalgia. In comparison to healthy controls, decreased levels of plasma cortisol and 24-hour free cortisol in urine have been detected in patients with fibromyalgia. There is also indirect evidence supporting fibromyalgia as a low-cortisol condition; it has several clinical features (e.g. fatigue, somnolence) that are common with other hypocortisolic states. However, the type of alterations in the HPA axis in fibromyalgia has not been consistent, and both hypo- and hyperactivity have been demonstrated (Clauw & Crofford 2003; Gupta & Silman 2004).

In a study by McBeth et al. (2007), it was tested whether alterations of the HPA axis would mediate the relationship between psychosocial risk factors and the onset of chronic widespread pain among previously pain-free subjects. The results indicated that subjects who responded to an exogenous steroid by higher serum cortisol levels and who had lower morning and higher evening salivary cortisol levels than normal were at increased risk of developing new-onset chronic widespread pain. However, high scores in the Illness Behavior Scale and reporting recent threatening life events remained independent predictors of symptom onset. These results suggest that chronic pain has both psychological and physiological antecedents (McBeth et al. 2007).

2.2.4 Psychosocial factors

Although major stress or adverse life events do not cause fibromyalgia *per se*, they may account for increased susceptibility to alterations of the stress-response system (Dadabhoy et al. 2008; Nicholl et al. 2009). Especially traumatic experiences in childhood or adolescence, or long-term psychological and emotional burden may increase vulnerability to chronic widespread pain, depression and fatigue, and hence precede or perpetuate the chronicity of the symptoms in fibromyalgia (Bailey et al. 2003; Hatcher & House 2003; Lampe et al. 2003; Jones, Power et al. 2009; McFarlane 2007).

According to Imbierowicz and Egle (2003), physical violence between parents was reported roughly seven times more often by patients with fibromyalgia than by patients with organic pain. Moreover, in the fibromyalgia group, history of sexual abuse and frequent physical maltreatment in childhood was reported several times more often than in the control group. In a study by Anderberg et al. (2000), up to 48% of fibromyalgia patients reported at least one negative life event in childhood, compared to 24% reported by healthy controls. Also in adult age, both physical and sexual abuse is highly prevalent in chronic pain patients; rates as high as 47% for sexual abuse and 61% for physical abuse are presented for fibromyalgia patients in tertiary care. However, it is likely that in population-based samples the experiences of physical or sexual abuse are less prominent than in samples from tertiary care (Goldberg et al. 1999; Goldberg & Goldstein 2000; Bailey et al. 2003).

Anderberg et al. (2000) noticed that fibromyalgia patients had experienced also other negative life events, such as divorce, serious illness of a family member or financial difficulties, significantly more often than their healthy controls. Furthermore, the patients with fibromyalgia experienced the impact of the adverse life events to be more negative and more severe in comparison to their healthy counterparts. By contrast, according to Haviland et al. (2010) only sexual and physical abuse was associated with the onset of fibromyalgia, whereas other major life stressors were not. Van Houdenhove, Neerinckx, Lysens et al. (2001) pointed out that no particular form of abuse is likely to be pathogenic as such; rather than that, psychosocial victimization can be seen as a global experience of being helpless and powerless in a long-lasting situation of neglect, abuse and unpredictability, which may lead to substantial long-term distress and thus increase the susceptibility to the symptoms that are typical in fibromyalgia.

2.3 Diagnosis and main symptoms

In addition to widespread pain, patients with fibromyalgia often suffer from fatigue, sleeping disorders, mood disturbances, and difficulties in cognitive and memory functions. Patients may also complain of a rich variety of other symptoms, e.g. persistent headache, irritable bowel, impaired motor control, paresthesias, balance problems and sensitivity to sensory stimuli (Arnold et al. 2008; Sim & Madden 2008; Watson et al. 2009; Wolfe et al. 2010). In the following, the diagnostic criteria for fibromyalgia from the year 1990 (ACR-1990) (Wolfe et al. 1990) and the updated version ACR-2010 (Wolfe et al. 2010) are presented. Thereafter, the core symptoms of fibromyalgia are introduced in detail.

2.3.1 Diagnostic criteria for fibromyalgia

Historically, conditions similar to fibromyalgia have been reported under different names for hundreds of years. In the late 16th century Guillaume de Baillou used the term ‘rheumatism’ to describe muscular pain. As early as in the mid-19th century it was noticed that when certain painful spots were palpated they produced pain in other regions. In 1904, Sir William Gowers suggested the word ‘fibrositis’ to be used for the condition, believing erroneously that inflammation was a key feature of ‘muscular rheumatism’. Later a wide range of terms has been used to describe the same phenomenon, e.g. myo-fibrositis, myofascitis, idiopathic myalgia, and psychogenic rheumatism. In the late 1970s the term ‘fibromyalgia’ was introduced, and since then attempts have been made to define it unequivocally (Chaitow 2000). However, it was not until 1990, that the first diagnostic criteria for fibromyalgia were published by the American College of Rheumatology (ACR). The criteria comprised two factors: widespread pain for at least 3 months and tenderness on digital palpation in at least 11 of 18 tender point sites located in all quadrants of the body (Wolfe et al. 1990). The criteria are presented in detail in Table 1.

Although the ACR-1990 criteria for fibromyalgia are widely accepted and used in both clinical settings and in research, several questions remain to be discussed. Firstly, although women are only more 1.5 times more likely to have widespread pain than men, they are 10 times more likely to have 11 or more tender points on digital palpation due to a lower threshold for pain. Moreover, population-based studies show that tender points are strongly associated with distress, which is also more prevalent in women. Thus, emphasis on the tender point count as a diagnostic criterion may have caused a gender bias in the prevalence of fibromyalgia (Clauw & Crofford 2003; Amital et al. 2006; Williams & Clauw 2009).

TABLE 1 Diagnostic criteria for fibromyalgia ACR 1990 (modified from Wolfe et al. 1990).

Criterion	*Definition*
History of widespread pain	Pain is considered widespread when all of the following are present: • Pain on the left side of the body, • Pain on the right side of the body, • Pain above the waist, • Pain below the waist. • In addition, axial skeletal pain must be present (cervical, thoracic or low back pain). Widespread pain must have been present for at least 3 months.
Pain on tender point sites	Digital palpation should be performed with an approximate force of 4 kg. Pain (not only tenderness) must be present in at least 11 of the following 18 tender point sites: • **Occiput**; bilaterally • **Low cervical spine** (C5-C7); bilaterally at the anterior aspects of intertransverse spaces • **Trapezius;** bilaterally at midpoint of the upper border • **Supraspinatus**; bilaterally at origins above the scapula spine • **Second rib**; bilaterally, at the second costachondral junctions • **Lateral epicondyle**; bilaterally 2 cm distal to the epicondyles • **Gluteals;** bilaterally in upper outer quadrants of the muscle • **Greater trochanter;** bilaterally posterior to the trochanteric prominence • **Knee;** bilaterally at the medial fat pad proximal to the joint line

Secondly, it has been suggested that the cut-off point of 11 tender points does not take into account the fluctuating nature of fibromyalgia. In fibromyalgia the tenderness seems to change on a day-to-day basis, and thus some patients with severe symptoms but fewer than 11 tender points on palpation would fail to satisfy the ACR-1990 criteria (Wolfe 2010). Finally, tender points and widespread pain do not seem to be able to capture the essence of fibromyalgia; i.e. a disorder with multiple symptoms, which in most cases include fatigue, sleeping problems, depression and cognitive dysfunction (Katz et al. 2006).

Therefore, in 2010 a suggestion for new diagnostic criteria was published introducing a combination of widespread pain index (WPI) and symptom severity scale (SS) (Appendix 1). The researchers suggest that a patient would fulfill the diagnostic criteria for fibromyalgia if the following three conditions were met: symptoms have been present for at least three months, WPI is at least 7/19 and SS at least 5/12 and the patient does not have a disorder that would otherwise explain the symptoms (Wolfe et al. 2010). In the new criteria the tender point examination as a diagnostic tool would thus be abandoned, although a thorough physical examination is still recommended (Wolfe 2010). However, more research is required to implement the new criteria into practical work.

2.3.2 Chronic widespread pain

Pain is an unpleasant and emotionally arousing sensory experience that signals the presence of damaging or life-threatening events, such as traumatic injury or infection. Acute pain promotes escape behavior, and thus contributes to survival, whereas chronic pain is maladaptive, evokes human suffering and decreases life expectancy (Diatchenko et al. 2006). Pain is considered to be widespread when it is present at least in three quadrants of the body, whereas chronicity is defined as experienced pain at the same level for at least 3 months (Aaron & Buchwald 2003). However, according to the diagnostic criteria for fibromyalgia, widespread pain must be present in all four quadrants of the body (Wolfe et al. 1990).

The location of the pain in fibromyalgia is often difficult to pinpoint; patients describe the pain as deep, dull ′achiness′ or ′hurt all over′, and it is experienced both when active and when resting (Arnold et al. 2008; Sim & Madden 2008). Furthermore, individuals with fibromyalgia display muscular tenderness, diffuse hyperalgesia, and allodynia (Ablin et al. 2008). Fibromyalgia patients rate their level of pain intensity twice as high as patients with rheumatoid arthritis (Laursen et al. 2005). However, pain severity in fibromyalgia may vary between patients as well as fluctuate in a particular patient at different points of time (Ablin et al. 2008). Follow-up studies indicate that widespread pain in patients with fibromyalgia is difficult to treat and that these patients rarely show improvement. Baumgartner et al. (2002) noticed that the level of pain in fibromyalgia increased or remained at baseline level in the majority of the patients, whereas only 18% improved within the six-year follow-up. Papageorgiou et al. (2002) noticed that participants, who were over 50 years of age and reported also other somatic symptoms and daytime tiredness at the baseline, were most likely to report chronic widespread pain (CWP) in the follow-up seven years later. In a qualitative study by Lempp et al. (2009) patients expressed that pain takes its toll both physically and mentally, and that they had no recollection of any pain- free time in their lives since diagnosis.

2.3.3 Fatigue

Fatigue can be defined as a subjective feeling of low vitality that ranges from tiredness to severe exhaustion and that disrupts daily functioning. Tiredness is a common short-lived physical experience, which in most cases disappears with rest, whereas exhaustion is labeled with depressive symptoms, work-related disability and physiological alterations of the endocrine functions (Sonnenschein et al. 2007). In fibromyalgia, fatigue is often characterized with non-restorative sleep, daytime tiredness and physical and mental exhaustion which affect different aspects of patients' daily lives (Crooks 2007; Arnold et al. 2008; Sim & Madden 2008). Fibromyalgia patients frequently show a pattern of day-to-day variability in vitality and fatigue, and they rate the overall level of daily fatigue higher than patients with rheumatoid arthritis or osteoarthritis (Zautra et al. 2007).

Crooks (2007) noticed that sleeping problems and fatigue force fibromyalgia patients to change their daily routines and to pace their activities to manage the symptoms. More than 80% of the participants reported that they needed to lie down and rest during the working day, and almost 70% napped during the day. Söderberg et al. (2002) emphasized that fatigue expressed by women with fibromyalgia is quite a different experience compared to the tiredness expressed by healthy women. In their study, women with fibromyalgia described fatigue as a bodily burden, as a feeling of being absently present, and as an invisible obstacle one constantly have to struggle with.

The causation of fatigue in fibromyalgia can be explained in several ways. Theadom et al. (2007) pointed out that up to 99% of fibromyalgia patients reported poor sleep quality, which in turn significantly predicted increased pain and fatigue in a long perspective. However, the relation between sleeping problems and pain may be reciprocal; research shows that on the one hand, disturbed sleep causes increased pain, and on the other, increased musculoskeletal pain causes sleeping disorders (Haack & Mullington 2005; Moldofsky 2008).

Secondly, fatigue can be aggravated by physical activities causing muscular fatigue even for several days afterwards. This may result in decreased activity due to fear of pain, which in turn leads to a vicious circle of decreasing muscle strength and increasing neuromuscular fatigue (Vollenstand & Mengshoel 2005). However, Valkeinen (2007) noticed that in fibromyalgia patients the time course of delayed onset of muscular soreness (DOMS) after fatiguing muscle strength exercise was comparable to healthy controls, which supports the view that neuromuscular fatigue may be caused by physical inactivity, rather than by fibromyalgia as such.

Thirdly, it is suggested that psychosocial distress and depressive symptoms may have a mediating role in the development of fatigue in chronic widespread pain. Nicassio et al. (2002) showed that perceived depression explained 18% of the variability of fatigue. Hadlansmyth and Vowles (2009) noticed that depression and fatigue were significantly correlated to another and to perceived disability, especially in terms of decreased psychosocial functioning. Moreover, Theadom and Cropley (2008) noticed that participants with fibromyalgia had significantly higher levels of perceived stress than healthy controls. Stress, in turn, was significantly associated with higher daytime dysfunction, pain and general fatigue.

2.3.4 Depression and anxiety

Mental problems, such as depression and anxiety, are often present in fibromyalgia and other chronic pain-related conditions. Although these symptoms usually remain on a mild or moderate level, patients with fibromyalgia rate their severity of depression higher than patients with rheumatoid arthritis or osteoarthritis (Parrish et al. 2008). Among patients with fibromyalgia, the prevalence of depression ranges from 20% to 71% (Bradley & Alberts 1999; Fietta et al. 2007; Cöster et al. 2008; Fuller-Thomson et al. 2011). In

Finland, 67% of the female fibromyalgia patients of a rheumatology clinic had a depression diagnosis, in contrast to 26% of the controls with other rheumatic conditions (Rahinantti 1998), whereas in general population the prevalence of depression is estimated to range from six to nine percent (Lindeman, et al. 2001). Also gender differences in the prevalence and impact of depression in chronic pain are reported; women are not only more susceptible to depression, but also more vulnerable to depression-related disability than men (Hirsh et al. 2006; Keogh et al. 2006).

Cohen et al. (2002) found significant overlap between fibromyalgia and posttraumatic stress disorder (PTSD). In their sample, 57% of patients with fibromyalgia had clinically significant levels of PTSD symptoms, such as flashbacks, re-experiencing, fear-avoidance behavior, or hypervigilance. Thieme et al. (2004) noticed that 32% of fibromyalgia patients revealed an anxiety disorder, whereas 35% reported a mood disorder. The researchers pointed out that these ratings are three times higher than the prevalence of psychiatric disorders in general population, but comparable to other chronic pain syndromes. However, several studies indicate that fibromyalgia patients with co-morbid PTDS seem to have more pain and distress and lower functional ability as well as lower health-related quality of life in comparison to other fibromyalgia patients (Amir et al. 1997; Taylor & Jason 2002; Cohen et al. 2002; Nicholl et al. 2009).

2.3.5 Cognitive problems

Chronic pain patients seem to perform poorly in complex cognitive tasks that require intensive attention and maintenance of concentration (Pirttilä & Nybo 2004). When fibromyalgia patients' ability to deal with stimulus competition (so called cognitive bias) was assessed, their performance declined markedly as the stimulus competition increased (Leavitt & Katz 2006). Similarly, Dick et al. (2008) noticed that in comparison to controls, individuals with fibromyalgia showed significant cognitive disruption, especially in demanding tasks. Deficits in psychomotor speed, memory problems and decline in language processing were also reported. When the pain scores were accounted for, the differences between patients and healthy controls disappeared, which refers to the significance of persistent pain in cognitive disruption.

Park et al. (2001) studied memory functions in fibromyalgia patients and their age-matched and 20 years older healthy controls. Results showed that fibromyalgia patients' memory was substantially impaired when compared with age-matched controls, and was comparable to controls that were 20 years older. In a qualitative study by Arnold et al. (2008), the participants with fibromyalgia explicated that they were not able to operate on their earlier level of acuity in work-related tasks. The participants felt more disorganized than before, and had difficulty with planning. Moreover, they were constantly worried over their work ability due to the cognitive and memory deficits. Parallel experiences were reported in a qualitative metasynthesis on illness experiences in fibromyalgia by Sim and Madden (2008). The complaints and beliefs of impaired memory seem to be accurate in fibromyalgia patients; their perceived memory capacity correlates well with actual memory performance (Glass et al. 2005).

2.4 Functioning and quality of life in fibromyalgia

Several qualitative studies imply that living with fibromyalgia is a never-ending struggle with 'an unwilling body' as well as a struggle to maintain dignity (Söderberg, 1999; Mannerkorpi et al 1999; Werner et al 2004; Råheim & Håland 2006). The results on the natural history and impacts of fibromyalgia on everyday life in a long perspective are conflicting. On the one hand, the symptoms are usually progressive for years and spontaneous remission is seldom found. On the other hand, symptoms may be relatively stable and the quality of life may improve over time as the patients learn to cope with the symptoms (Mengshoel & Heggen 2004; Baumgartner et al. 2002; Sim & Madden 2008).

2.4.1 Functional limitations

According to ICF Core Set for widespread pain, life areas such as mobility, self-care and domestic life are largely affected by fibromyalgia (Cieza et al. 2004). In a study by Jones, Horak et al. (2009), middle-aged fibromyalgia patients (n=34) were compared with healthy age-matched controls to determine whether the patients differed in clinical tests of balance ability and fall frequency. It was noticed that fibromyalgia patients had significantly impaired balance in all five domains of the balance test; stability limits, anticipatory postural adjustments, reactive postural responses, sensory orientation, and stability in gait. The most difficult task for the patients with fibromyalgia was to quickly perform the Get Up and Go test with a secondary cognitive task (i.e. subtracting by 7's backward from 100, while walking). The researchers concluded that significant slowing of the walking speed when dividing attention to a secondary cognitive task reveals the need for increased attentional resources on balance and gait, which are normally automatically controlled. Moreover, a total of 37 falls over the last six-months were reported by fibromyalgia patients compared to 6 falls reported by healthy controls.

Jones et al. (2008) explored the self-reported physical functioning level of 1,735 female patients with fibromyalgia (average age 47 years). Every fourth respondent reported difficulties in self-care, and more than 60% reported difficulties in light household tasks, carrying or lifting loads, climbing up or down the stairs, or walking half a mile. Furthermore, 90% of the women reported difficulties in heavy household tasks and strenuous activities. The researchers compared these results to findings from other large population-based studies in which the same questionnaires were used, and concluded that functional ability of an average middle-aged fibromyalgia patient was worse than functional ability of an average community-dwelling woman in her 80s.

Lempp et al. (2009) pointed out that fibromyalgia affected not only the physical functioning, but also the social lives of the patients. Patients experienced loss of independence and a decrease in the amount and quality of social relationships due to fibromyalgia. Similarly, Råheim and Håland (2006) saw holding on to participation on important arenas to be an essential part of successful coping strategies. Crooks (2007) explored the daily geographies of women with fibromyalgia and noticed that for many women the loss of hobbies and a reduction of recreational activities and social engagements were in the core of changes in their life worlds and daily geographies. According to Arnold et al (2008), the unpredictability of fibromyalgia symptoms was perceived to cause difficulties in participating in regular social activities or maintaining friendships and making new friends. Moreover, the invisibility of fibromyalgia presented patients with an additional social difficulty: negative attitudes and perceived lack of acceptance by other people (Hieblinger et al. 2009). As a result of impaired physical and psychosocial functioning the patients with fibromyalgia may easily become home-bound (Crooks 2007).

In the family context, fibromyalgia does not only have impact on sharing domestic duties or family responsibilities but also on emotional and intimate relations. Women find it challenging to take care of children or elderly parents due to the physical and mental fatigue and often express feelings of guilt and shame because of not having the energy to be emotionally involved in social relations (Hallberg & Carlsson 1998; Mannerkorpi et al. 1999; Johansson et al. 1999; Arnold et al. 2008). In a narrative study by Smith (2003) the participants told how they needed to push themselves to continue with their obligations to care for others, and felt guilty about needing help and about sometimes focusing on themselves. Moreover, Ryan et al. (2008) noticed that two in three fibromyalgia patients reported limitations in intimate and sexual life due to fatigue and pain. In addition to loss of sexual desire or avoidance of sexual intercourse, negative self-image – loss of womanliness – is also frequently reported by women with fibromyalgia (Smith 2003; Ryan et al. 2008).

2.4.2 Work ability

Kivimäki et al. (2007) noticed that the risk for work absenteeism due to fibromyalgia was almost twofold in comparison to employees with no chronic conditions. Furthermore, the probability of sickness absence increased significantly if fibromyalgia was associated with other co-morbid chronic conditions, such as depression or osteoarthritis. According to Blyth et al. (2003), work performance may be severely disturbed merely by intensive, persistent pain. They concluded that the negative impact of chronic pain on work ability cannot be captured only by the days of absence, but decrease of work-effectiveness should also be discussed.

Although employed fibromyalgia patients have better health status than unemployed ones, employment as such does not seem to provide a protective health benefit in a long perspective (Reisine et al. 2008). Fibromyalgia symptoms are reported to cause difficulties in work performance even of young, recently diagnosed patients. Both physical efforts and psychosocial distress at work increased the intensity of the pain and other symptoms causing spells of sick leaves. Substantial physical, psychological and social difficulties were constant in a one-year follow-up, but the older patients seemed to cope better than the young patients, who had small children and thus few opportunities to rest (Liedberg et al. 2006). In the studies included in a review by Henriksson et al. (2005), 34-77% of the patients were able to continue working despite fibromyalgia, especially with adjustments concerning work tasks and working hours. On the other hand, 20-50% of the patients were on permanent disability pension or other disability benefits. However, the researchers point out that it is difficult to compare results from different countries because of the differences in social benefit systems, which also influence the possibilities of remaining in the labor market in spite of disability.

2.4.3 Quality of life

Defining quality of life is not easy or unequivocal. Each individual's unique circumstances and experiences shape the perception of quality of life, and assessment of quality of life is thus always subjective. The general or global meaning of quality of life may be anchored to an individual's social or economic status or living arrangements, as well as to culture, personal values, happiness, or spiritual well-being (Schirm 2009). The concept of health-related quality of life is more specific, and is usually defined in relationship to physical health, emotional and mental well-being and functional status. Health-related quality of life has become an important outcome measure in chronic conditions, especially if full remission is not possible or if the condition threatens one's functioning, work ability or perceived autonomy substantially (Walker & Littlejohn 2007; Schirm 2009). Walker and Littlejohn (2007) emphasize that assessment of health-related quality of life in rheumatic conditions is critical regarding the impacts that e.g. poor mental well-being has on the condition itself: poor treatment compliance and increased mortality.

In fibromyalgia research, Medical Outcomes Survey 36 Items (SF-36) is commonly used as a generic instrument in the evaluation of health-related quality of life. SF-36 includes eight dimensions of health and well-being: physical functioning, role physical, role emotional, bodily pain, general health, vitality, social functioning and mental health (Ware & Sherbourne 1992). The SF-36 provides a possibility to compare the quality of life between healthy individuals and those with a chronic condition, or between different chronic illnesses (Walker & Littlejohn 2007). The Finnish 15D instrument, in turn, evaluates health-related quality of life in regard to mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental functions, discomfort and symptoms, depression, distress, vitality and sexual activity (Sintonen 2001).

Several studies show that health–related quality of life is perceived as lower by people with fibromyalgia, in comparison to healthy controls or to those with other rheumatic conditions or musculoskeletal disorders (Ofluoglu et al. 2005; Cöster et al. 2008; Wolfe, Michaud et al. 2010) or other chronic conditions (Burckhardt et al. 1993). Laursen et al. (2005) compared health-related quality of life in four pain patient groups: fibromyalgia, endometriosis, low back pain and rheumatoid arthritis. Fibromyalgia patients rated their quality of life significantly lower than the other patient groups in all dimensions of SF-36, except for physical function and general health. The researchers also found a significant correlation between the pain intensity and quality of life ratings. Verbunt et al. (2008) noticed that patients with fibromyalgia experience a lower quality of life as compared to the general population, to patients with chronic low back pain and to patients with complex regional pain. In comparison with patients with rheumatoid arthritis, fibromyalgia patients seemed to be more affected, especially in terms of mental health and social functioning. Moreover, Nicholl et al. (2009) noticed that anxiety and depression were the strongest independent predictors of poor health-related quality of life in individuals with new onset of chronic widespread pain.

Kukkurainen (2006) used the 15D instrument and noticed that patients with fibromyalgia rated their health-related quality of life lower than patients with diabetes, low back pain or hip surgery and almost as low as patients with spinal cord injury. However, during a one-year follow-up after a fibromyalgia-specific rehabilitation course the ratings improved in terms of sleeping, mental functions, distress, discomfort and symptoms, usual activities and vitality, although the perceived level of pain and sleeping problems remained unchanged. Furthermore, it was noticed that the stronger the sense of coherence, the higher the health-related quality of life.

2.5 Treatment

As the etiology and pathogenesis of fibromyalgia are not fully understood, no single cure for the condition has yet been found. According to current evidence, tailored medication, moderate-to-high intensity exercises and cognitive-behavioral education, or a combination of these are recommended to relieve the symptoms and to increase functional ability and health-related quality of life in fibromyalgia (Sarzi-Puttini et al. 2008; Buskila, 2009; Häuser et al. 2010).

2.5.1 Pharmacological treatment

Fibromyalgia has been treated by a wide range of drugs, such as antidepressants, opioids, relaxants and antiepileptic drugs, but only few seem to have clear-cut benefits in randomized controlled trials (Sarzi-Puttini et al. 2008). Recently, three drugs were accepted for the treatment of fibromyalgia in USA and are also recommended in Europe: pregabalin, milnacipran and duloxetine (Buskila 2009; Häuser, Thieme et al. 2010).

Pregabalin is an antiepileptic drug that limits neuronal excitation and enhances pain inhibition. Pregabalin reduces the release of several neurochemicals, including noradrenalin and substance P. Patients treated with pregabalin showed significant improvement in pain, sleep and fatigue and in health-related quality of life in comparison to patients who were treated with a placebo (Crofford 2008; Buskila 2009; Williams & Clauw 2009). The adverse effects of pregabaline are dose-dependent dizziness, somnolence, weight gain and peripheral edema. Although the severity of the side effects is generally mild, they may limit the utility of antiepileptic drugs in some patients (Buskila 2009).

Antidepressants have been used in the treatment of fibromyalgia for years. The most widely studied drug is amitriptyline, which is reported to help patients with fibromyalgia by improving sleep and reducing morning stiffness. It is, however, poorly tolerated by many patients (Sarzi-Puttini et al. 2008). The effects of milnacipran and duloxetine, which are dual reuptake inhibitors of serotonin and norepinephrine, were evaluated in patients with fibromyalgia in multicenter trials. Substantial improvements were demonstrated in physical functioning, level of fatigue and degree of self-reported disability as well as in self-reported pain when compared with baseline and with placebo treatment (Crofford 2008; Sarzi-Puttini et al. 2008; Buskila, 2009; Williams & Clauw 2009). The adverse effects of these drugs may include nausea and headache, although the side effects are in most cases reported to be mild or moderate (Crofford 2008).

Anti-inflammatory drugs (NSAID) that are commonly used in treatment of pain in other rheumatic conditions are generally not beneficial in treatment of fibromyalgia (Williams & Clauw 2009). However, tramadol has multiple analgesic effects in addition to anti-inflammatory effect; it inhibits serotonin and norepinephrine reuptake and it has some opioid activity. Fibromyalgia patients treated with tramadol showed significant improvement in pain and daily functioning in comparison to those who were treated with placebo. Tramadol is usually well tolerated but it may cause nausea, constipation, dizziness and somnolence. The use of opioids is not recommended in fibromyalgia due to the lack of research-based evidence in the treatment of this particular condition and due to habit forming and relatively severe side effects (Sarzi-Puttini et al. 2008; Häuser, Thieme et al. 2010).

2.5.2 Exercise therapy

The symptoms of fibromyalgia, such as musculoskeletal pain, sleeping problems and fatigue, combined with activity-induced muscular pain easily lead to inactivity (Crooks 2007) and fear-avoidance behavior (de Gier et al. 2003) and may thus cause physical deconditioning. Therefore, physical exercise on a moderate intensity level is recommended for patients with fibromyalgia (Mannerkorpi & Iversen 2003; Häuser et al. 2010).

Mannerkorpi et al. (2000) compared a six-month pool exercise combined with an educational program with a control group that was instructed to continue with their usual activities. The exercise group improved in aerobic performance, symptom rating, physical and social function and anxiety and depression when compared with the control group. The improvements remained in a six-month follow-up, and improvements in aerobic capacity, pain, fatigue and social function remained even after two years (Mannerkorpi et al. 2000; Mannerkorpi et al. 2002).

Recently Mannerkorpi et al. (2010) studied moderate-to-high intensity Nordic walking in patients with fibromyalgia in a randomized controlled trial. The Nordic walking group (NW group) exercised under supervision twice a week with moderate to high intensity for 15 weeks. The control group participated in low-intensity exercise sessions once a week for 15 weeks. The NW group showed significant improvement in physical capacity measured with six-minute walking test, and a significantly reduced heart rate in ergometer test in comparison to baseline and to controls. Limitations in daily life and overall health status improved significantly in the NW group. However, in pain ratings there were no differences between the two groups. In follow-up after six months, a significant decrease in general and physical fatigue was seen in both groups, indicating that regular exercise over a long period of time, even when on low intensity level, is beneficial in reducing fatigue in fibromyalgia.

Häuser, Klose et al. (2010) conducted a meta-analysis of randomized controlled trials (RCT) comparing different types of aerobic exercises in the treatment of fibromyalgia. Twenty-eight RCT studies totaling almost 2,500 patients were analyzed. Aerobic exercise in general was found to be beneficial in regard to reduced pain, fatigue, depressed mood, and improved health-related quality of life and physical fitness. However, aerobic exercise had no effect on sleep problems, and continuing exercise was found to be necessary to maintain the positive effects on pain in a longer perspective. Moreover, no differences were reported between different exercise types (e.g. walking vs. aerobics), and there was no evidence of superiority of water-based over land-based exercises. Very low intensity exercise (<50% of maximal heart rate, maxHR) was found to be ineffective, and even with moderate intensity (50-80% of maxHR) the positive effects on symptom reduction could be seen only after exercising 2-3 times a week for 4-6 weeks. These results confirm the earlier recommendations of the Ottawa Panel Guidelines for aerobic exercise in fibromyalgia (Brosseau et al. 2008a).

Strength training is recommended for patients with fibromyalgia in order to avoid the decline of muscle strength and physical functioning that is caused by inactivity (Mannerkorpi & Iversen 2003). Häkkinen et al. (2002) compared fibromyalgia patients with healthy controls in a randomized controlled trial where patients either participated in a 21-week strength training program or continued with their usual activities. The results showed improvement in muscle strength, muscle-firing patterns (EMG activity) and in mood in the exercise group in comparison to controls. In comparison, Kingsley et al (2005) conducted a 12-week strength training program for patients with fibromyalgia and wait-listed controls. The results showed significant improvement in strength and in functioning in routine household tasks in comparison with both baseline measurements and the controls. Valkeinen et al. (2006) pointed out that regular strength training twice a week with progressively increasing loading (from 50% to 80% of maximum) led to significant improvements in muscle strength in post-menopausal women, and that it did not exacerbate, but slightly attenuated perceived pain and fatigue. In a meta-analysis by Brosseau et al. (2008b) the positive effects of strength training were indicated in terms of pain relief, increased muscle strength and improved health-related quality of life and a decrease in perceived physical disability, depression and anxiety. They recommended individualized exercise instructions to increase exercise adherence and to avoid drop-out due to exercise-induced pain, which is a common problem, especially in sedentary patients with fibromyalgia.

2.5.3 Cognitive-behavioural therapy

Patients find fibromyalgia emotionally distressing and difficult to understand and they do not expect the medical treatments to be effective. There again, inability to understand the experienced symptoms seems to increase anxiety, desperation and tendency to catastrophic thinking (van Wilgen et al. 2008; van Ittersum et al. 2009). Research indicates that pain catastrophizing and pain-related anxiety and fear are related to poor adjustment to pain. Patients with greater self-efficacy are more likely to respond favorably to treatment programs and to experience better outcomes (Keefe et al. 2004; Sowden et al. 2006; Sarzi-Puttini et al. 2008).

Cognitive-behavioral therapy (CBT) is a generic term that comprises a wide range of treatment modalities, all of which are designed to educate the patient, to facilitate self-management and to improve functioning. The therapy can include for example education for stress management, relaxation exercises, problem solving and cognitive re-constructuring. In fibromyalgia, cognitive-behavioral approach aims at reducing anxiety, increasing treatment compliance, enhancing self-efficacy, improving coping skills and drawing attention away from the symptoms (Sarzi-Puttini et al. 2008). CBT as a stand-alone treatment has produced significant short-term effects on pain severity, pain beliefs, coping skills and self-efficacy in patients with fibromyalgia (Burckhardt 2005). However, cognitive-behavioral education is often combined with other treatment modalities, such as exercise or medication. In fibromyalgia, combining CBT and aerobic exercise seems to be effective, resulting in significant improvements in pain, pain behavior, fatigue, general wellbeing, distress and physical fitness (Mannerkorpi et al 2000; Gustafsson et al 2002; Williams 2003; Lemstra & Olszynski 2005; van Wilgen et al. 2007). Moreover, group-based interventions that combine educational issues (e.g. on etiology, symptoms and self-management of fibromyalgia) with moderate aerobic exercise have the additional benefit of peer support, which gives possibility to sharing experiences and knowledge as well as to social comparisons with other people with similar illness (Williams 2003; Kukkurainen 2006). Based on current evidence, cognitive-behavioral therapy is suggested to be an essential part of multiprofessional and multimodal rehabilitation interventions of patients with fibromyalgia (Burckhardt 2005; Häuser et al. 2009; Häuser, Thieme et al. 2010).

3 PURPOSE OF THE STUDY

Despite the growing knowledge base on causes and consequences of fibromyalgia, the long-term effects, recovery (or non-recovery) and meaning making processes have rarely been studied from the point of view of the patients. In this study, fibromyalgia was approached from the perspective of patients with a long illness history. The purpose of the study was to explore the participants' experiences of the impacts of fibromyalgia in their daily lives and functioning and to elucidate how they reflected upon the rehabilitation as part of their illness-recovery process from the vantage point of the present. Furthermore, the purpose was to investigate how the participants interpreted and re-constructed their life events and illness experiences in a life story several years after a fibromyalgia-specific rehabilitation course. The specific aims of the study were as follows:

1. To explore how fibromyalgia patients with a long illness history describe and reflect upon their work ability and functioning in their life stories (Publications I-II).
2. To explore which elements of rehabilitation are perceived as meaningful for the participants in their illness–recovery process (Publication III).
3. To examine how fibromyalgia patients with a long illness history express, interpret and reconstruct their life events and their illness experiences as a narrative (Publication IV).

4 RESEARCH METHOD

4.1 Narrative approach as a theoretical frame

The epistemological beliefs of how knowledge of reality can be achieved flows necessarily from the ontological beliefs that concern the nature of reality (Schwandt 2000; Giacomini 2010). In the narrative approach, the realm is understood as individually constructed, and it differs depending on time, place, context, culture, social status and earlier experiences of each individual (Heikkinen 2002). Narrative research has roots in the hermeneutic-phenomenological tradition, more specifically in social constructivism that focuses on exploration of lived experiences of individuals as well as on the language that structures the experiences (Bury 1982; Polkinghorne 1996). According to Ricoeur (1984, 1992) narrative time and temporality are not limited to chronological time; narrative understanding of temporality comprises person's expectations of the future, reflections of past experiences and the present time where the narrative is actually explicated as a story. Furthermore, the person is not merely the one, who tells the story, or merely the one about whom the story is told, but she "appears both as a reader and the writer of her own life" (Ricoeur, 1987). Therefore, narratives can be seen as a fundamental human way of giving meaning to one's experiences and creating narrative identity. In both telling and interpreting experiences, narratives can mediate between the inner world of feelings and thoughts and the outer world of the observable state of affairs (Garro & Mattingly 2000).

Hänninen (2004) discusses the told narrative as a reflection of an inner narrative, i.e. the story we tell ourselves. While the told narrative functions through communication, the inner narrative is linked to non-linguistic psychological processes regarding identity, conceptions of relations between events, moral commitments, or ways of understanding the past. On one hand the inner narrative can never be fully expressed in a told narrative, but on the other hand, dialogue with others may prompt the person to focus on previously unnoticed experiences and hence the told narrative can shape the inner narrative (Hänninen & Valkonen 1998; Hänninen 2004).

Bruner (1991) discusses the *tellability* of the story in terms of canonicity and breach: what happened and why is it worth telling? He also sees narratives of one's own life as both privileged and troubled in the sense that they are reflexive; the narrator and the central figure of the story are the same. The life stories do not "happen" in the real world, but are constructed in people's minds and therefore, they are both subjective and context-bound (Bruner 2004). Similarly, Riessmann and Speedy (2007) highlight that personal narratives can be differentiated from other forms of discourse in terms of *sequence* and *consequence,* through which the events are selected, connected and evaluated as meaningful for the particular listener. Moreover, Atkinson (2001) points out that a told life story is not meant to be understood as a historical reconstruction of life events; rather than that, it may give perspectives to how the individuals see themselves at a given point of their life and how they want others to see them. In summary, personal narratives do not reach for objectivity; rather than that they emphasize subjectivity and positionality (Riessmann 2001).

Chronic illness, such as fibromyalgia, can be seen as a disruption in the anticipated life course that forces one to re-evaluate one's life, identity and future *with* the illness and *despite* it. On the one hand, when the life story is re-constructed and re-told over and over again, the illness also becomes a part of the account and new meanings can be given to illness experiences (Bury 1982). On the other hand, telling a life story helps the patient to repair the mental and physical damage the illness has done to the body. Therefore, illness narratives serve several purposes: to construct illness experience, to construct life history, to make illness understandable and to collectivize the illness experience. Through illness narratives, patients with a chronic illness try to find coherence and continuity in their self-perception and identity (Hydén 1997). Moreover, narratives can elucidate values, attitudes, and fears that are ascribed to various experiences, and thus reveal important issues linking the individual illness experiences, identity and culturally accepted conventions of talking about the given illness (Becker 1999).

The narrative approach is well applicable to fibromyalgia, where the patients strive to make sense of the fluctuating symptoms and of the disruption in the life course that is caused by the illness and its consequences. In this study the participants are understood as active agents, who are not only describing their life events, but who are also actively negotiating and re-constructing their life story by choosing and interpreting the events and by emphasizing different aspects of their experiences. The relationship between narrator and researcher inevitably affects the type and depth of the co-constituted story, and interpretation and understanding the experiences assumes subjectivity of both the narrator and the researcher. In research interviews, the impact of the interviewer in the narrative process is hence inescapable (Polkinghorne 1996, Riessman 2001; Randall et al. 2006).

4.2 Study design and participants

This doctoral thesis forms part of a wider follow-up study that was launched at the Rheumatism Foundation Hospital in Heinola in 2007. In the follow-up study both quantitative and qualitative data were collected in order to elucidate the level of symptoms, perceived current functioning, and health-related quality of life of patients with a long history of fibromyalgia. During 1999-2001 seventeen fibromyalgia-specific rehabilitation courses were completed in the Rheumatism Foundation Hospital, and the participants (n=169) of these courses were approached in the follow-up study.

The rehabilitation courses were funded by the Social Insurance Institution (SII), and the regional offices of SII selected the patients based on their own applications and a doctor's referral. The fibromyalgia-specific courses were conducted in groups of 10-12 participants, and the entity of 17-20 days was divided into two or three intensive in-patient periods within six months. The program comprised lectures by professionals, group discussions, physical exercises, relaxation exercises and some individual treatments, but the emphasis was on education and counseling, instead of treatment as such (see also Kukkurainen 2006).

A letter with information on the follow-up study, a consent form and a questionnaire was sent in May 2007 to all eligible participants (n=152) of the above-mentioned courses. Of those 17 who were not reached, one had died, one was unable to communicate due to other illness, four had denied access to their files, and the remaining 11 had no permanent address in Finland. Total response rate was 64%, and 47 respondents gave written informed consent to participate in the narrative interview study. For the narrative interview study a purposive sample of twenty women was recruited, aiming at maximal variation in terms of age, professional background and location (see also Curtis et al. 2000). Sampling is presented in Figure 1.

The sample consisted of women aged 34-65 years (mean age 54) from both urban and rural areas of the country. Their professional background can be considered to be typical to Finnish women: health care and social work in different settings, teaching, office or industrial work. All participants of the present study were diagnosed with fibromyalgia according to ACR-1990 criteria. Their reported symptom duration ranged from 10 to 30 years (mean 17 years), but the majority of the participants were not diagnosed with fibromyalgia until the late 90s; time since diagnosis was on average 11 years (range 10-15 years). Overview of the characteristics of the participants is presented in Table 2.

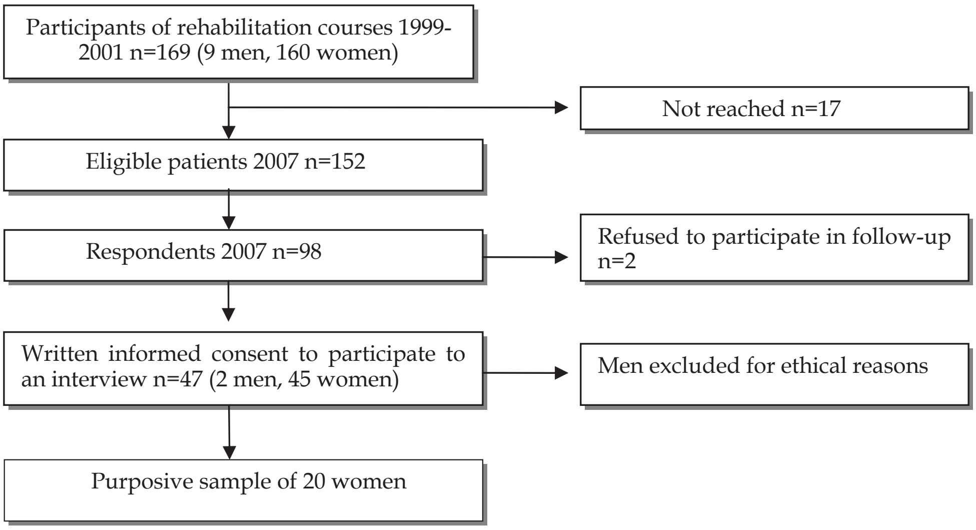


FIGURE 1 Sampling flow chart.

TABLE 2 Overview of the participants.

Age	n
-45	2
46-50	3
51-55	5
56-60	5
61-	5
Educational background	
Basic education	3
Vocational education	9
College or university degree	8
Location	
Rural	7
Suburban	6
Urban	7
Living	
Alone	5
With spouse	11
With family (incl. children)	4
Labour market status	
Full time work	6
Part time work/ unemployed	2
In re-education	1
On sick leave	3
Disability pension	7
Retired (due to age)	1

4.3 Ethical issues

The study design and methods were approved by the Ethical Committee of the Joint Authority for Päijät-Häme Social and Health Care, and written informed consent was obtained from the participants before arranging the interviews. Only two men volunteered for the interview study, and because it was possible, although unlikely, that they could have been identified due to the small number of men in the rehabilitation groups, they were excluded from the interview study.

At the beginning of each interview the context and the purpose of the study were explained and the participants were reminded of the right to withdraw from the study at any point. The participants were also asked if recording the interview was allowed and assured that the recording device could be switched off any time. However, only during two interviews did the participants ask that the recording device be switched off for a while when telling about severe, intimate life events. The recording was continued later following the permission of the participant. The author of this doctoral thesis conducted all the interviews and carried the main responsibility for the qualitative data analysis. Furthermore, the author wrote the drafts of the original articles and revised them after discussions with the co-authors.

In the examples presented in the original articles all personal identifiers have been removed or disguised so that the persons described are not identifiable and cannot be identified through the details of the story. Furthermore, different pseudonyms are used in each publication to protect the identity and integrity of the participants.

4.4 Data collection

The interviews followed the ideas introduced by Rosenthal (2003) and Wengraf (2001), who suggested opening the interview with a spontaneous narrative and then continuing with open questions to expand the narrative. In this study the participants were given a short instruction to prompt spontaneous storytelling: ”Tell me your life story, you can start from the point of your choice and include whatever you find necessary.” The interviewer made conscious efforts to show active and empathetic listening and did not interrupt the narrative process until the interviewee signaled that she had finished.

In the second part of the interview, the interviewer asked questions emerging from the account to expand and deepen the story-telling. Typical questions were: ”What happened after you…?”, “Could you tell me more about …” or “Can you give an example of…?” The interview session ended with an informal discussion, and the interviewee was encouraged to ask any questions concerning the research project or current treatment modalities of fibromyalgia or to comment on her own contribution. This discussion also gave the interviewer a possibility to observe the interviewee for a while, and make sure that she was at ease, as reminiscence of earlier life events may be mentally burdensome. The length of the interviews varied from 2 to 4 hours; typically 2.5 hours was used for the whole session.

4.5 Data analysis

The analysis of the data was inspired by the paradigmatic and narrative analysis introduced by Polkinghorne (1996), by the analysis of the episodes by Labov and Waletsky (1967/2003), and by the analysis of rhetorical means (such as *entrance* and *exit talk*) introduced by Riessmann (2001). According to Polkinghorne, paradigmatic analysis of narratives is used to produce taxonomies and categories out of the common elements across the database, whereas narrative analysis can be used to produce explanatory stories. Furthermore, he emphasizes that before narrative data can be coded and organized into paradigmatic categories, the stories need to be understood as stories. Therefore, in this type of hermeneutic process, the researcher must undertake '*the to-and-fro movement from part to whole and from whole to part*' in order to reach deep understanding of the data (Polkinghorne 1996).

In this study the interpretation of the data began already during the interviews where the interviewer was to be sensitive and alert to notice the key points as well as the gaps of the spontaneous narrative that needed to be fulfilled in the second part of the interview. The recorded material of each interview was listened to several times and transcribed verbatim within the following days. In the first stage of the analysis the orientation was towards the content of the data: *what* were the interviewees talking about? The topics and subtopics that emerged from the data were listed for further analysis. In most cases the life-stories were not represented as a single story, but rather as a series of small, parallel episodes. The episodes of each life story were identified and then organized chronologically in order to see the links between different events and experiences and to reconstruct a condensed core story of 1-2 pages of each life-story. The following example of Maija's account illustrates the identification of episodes:

1. Maija begins with a condensed idea of the episode: "*The last year at work was awful!* "
2. Then she describes the situation: "*I could sleep the whole weekend to reach some kind of balance before Monday... to be able to go to work again… I was really in poor condition… all aches and pains, but nobody really paid any attention to it. I didn't sleep at all or just maybe two hours, night after night. My head was buzzing and I felt dizzy but I tried to do my job all the same. The pain was awful. I couldn't stay still either... because of the pain. You just forced yourself to go on, even when you were totally exhausted*".

3. Maija closes the episode with a reflection of the situation and repeats the idea: *"Now afterwards I can admit that I was a fool to let it go so far. It was really nothing but agony, the whole last year!"*

In the final stage of the analysis main focus was towards the structure of the narrative i.e. *how* was the story told? Analysis aimed at narrative emplotment; finding common storylines or plots that combine the structure and content of several life-stories to a model-narrative. To do this, the storylines of all 20 interviews were re-analysed and compared to find recurrent structures in the narratives. Moreover, the rhetorical means that the participants used to combine different episodes, to signal turning points and meaningful experiences in the account, or to highlight the subject position that they took, when telling about different events, were analysed (see also Hydén 2005). The whole analysis process is illustrated in Figure 2.

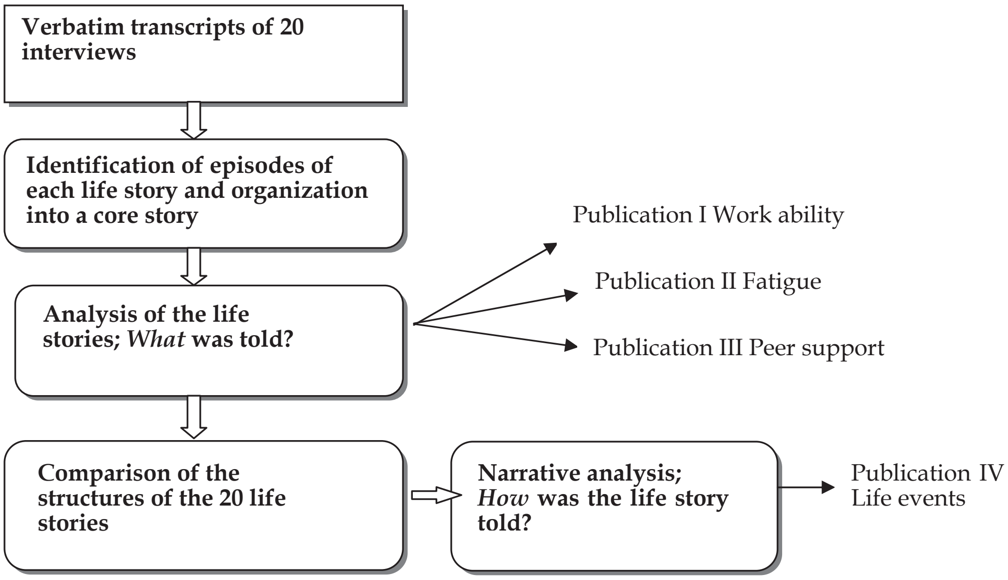


FIGURE 2 The analysis process.

5 FINDINGS OF THE STUDY

5.1 Fibromyalgia patients' perceived work ability and functioning (I-II)

The first purpose of this study was to explore how fibromyalgia patients with a long illness history describe and reflect upon their work ability and functioning in their life stories. In the interview data, work ability was a key issue through which the women reflected upon their experiences of illness and functioning. Four types of work ability experiences emerged from the data: 'confusion', 'coping with fluctuating symptoms', 'being in-between' and being 'over the edge'.

The 'confusion' experience reflected uncertainty in a new situation, but was often solved when more information on the symptoms and diagnosis was available. Experience of 'coping with fluctuating symptoms' was a success story; even when the fibromyalgia symptoms continued, they caused no substantial problems in relation to work ability. The 'in-between' experience represented a more complicated situation, leaving the patient somewhere between work ability and disability, and sometimes even between paid work and disability benefits. In the 'over the edge' experiences, return to work was perceived as unrealistic not only because of the physical, psychological, emotional and social limitations the women had, but also because of the unbearable life situation as such. In the data, early vocational rehabilitation interventions were in many cases missing, inadequate or started too late to be successful. In some narratives, these four themes of perceived work ability were consecutive and created a linear storyline from work ability to disability. However, it was more common that during the past few years, work ability had fluctuated back and forth between these four types of experiences, often in association with the life situation in general.

The functional limitations described by the participants included fluctuating difficulties in mobility and household tasks as well as in social and recreational activities. Moreover, memory problems and difficulties in concentration and cognitive skills were discussed by several participants. The nature and intensity of the constant pain was vividly described in the interviews. However, fatigue was the most common symptom in the data and many women found it to be the most problematic and disturbing symptom, even in comparison with chronic pain. Five themes regarding fatigue could be identified from the data: ‘sleepless nights’, ‘physical weakness’, ‘loss of mental energy’, ‘social withdrawal’ and ‘overwhelming exhaustion’. Sleeping problems were common and continuous and caused increased pain and daytime tiredness. Physical weakness caused problems in performing physically strenuous tasks at work or at home, or in physical activities. Many participants described vividly the perceived lack of mental energy and social withdrawal that had both largely affected their work ability. The participants also described changes that they had noticed in themselves; the earlier happy and socially active hardworking woman had turned into a depressed and constantly tired woman who withdraws from social situations. Furthermore, in some of the narratives the experiences of fatigue and depression seemed to overlap. This was especially apparent in the narratives describing ‘overwhelming fatigue’ where depressive symptoms, hopelessness and despair formed a substantial part of the experience, and which led not only to permanent loss of work ability but also to poor functioning in all daily activities.

The results indicate that fibromyalgia patients who are in a complicated life situation and suffer from severe symptoms may be at high risk of being permanently excluded from the labor market and would need innovative and well-timed rehabilitation interventions to support their empowerment, overall functioning and work ability.

5.2 Experiences of rehabilitation and peer support (III)

The second aim of the study was to explore which elements of rehabilitation were perceived as meaningful for the participants in their illness–recovery process several years after the rehabilitation intervention. The motifs and expectations for the rehabilitation course varied; some participants searched for more information, some wanted to ‘quit the rat race’ and some did not have any specific expectations. The majority of the women in the study had suffered from intense widespread pain and other symptoms for years or even decades before fibromyalgia diagnosis was confirmed. From the vantage point of the present, received peer support was acknowledged as the most important and meaningful element in the rehabilitation course. For many women the rehabilitation course was the first possibility to meet others with the same diagnosis. The encounters with peers appeared to be a significant turning point after struggling with uncertainty and negative attitudes of colleagues and health care professionals for years. One of the women put it clearly: “I*t was an amnesty*”.

The analysis revealed four themes regarding experiences of peer support: ‘permission to talk’, ‘need for experiential knowledge’, ‘reciprocity’ and ‘self-evaluation through comparison'. 'Permission to talk' was seen as the most rewarding experience during the rehabilitation course; the participants were allowed and encouraged to talk about the symptoms, the diagnosis and about the functional and emotional consequences of the illness that they experienced in their daily lives. Although information given by professionals was highly appreciated, the experiential knowledge provided by peers was seen as crucial to make the information easier to understand and digest. However, many participants expressed that their functional capacity and work ability had changed over the past years due to other health problems and ageing, and they were eager to get more up-dated information about treatment options of fibromyalgia and to share their experiences with others with a long illness history.

'Reciprocity' was an important element in peer support in the accounts of the participants. It included the idea of receiving support, comfort and understanding and giving those to others. The earlier experience of being odd, strange or an outsider was finally displaced by an experience of belonging to a group and not being alone with one's problems. In particular, mental health problems that were noticed in others forced the women to evaluate their own situation from a new perspective. Interestingly, when comparing to other participants in the fibromyalgia peer group, all the interviewees expressed that their own situation was less demanding and that their functioning was better than that of some others in the group. Self-evaluation through comparison seemed to be a continuous process that was initiated during the rehabilitation course but continues even today.

In summary, even if patients have a diagnosis, they often experience being 'not-heard' or 'not-believed' in their daily encounters with lay people and with health professionals. The results show that the meanings ascribed to peer support were mainly positive: finally daring to be oneself, feeling a sense of community and enhancing empowerment through validation of the illness experiences. Although seeing others with more severe functional disabilities or depression also raised some contradictory thoughts, the rehabilitation intervention and peer support seemed to prompt the process of reconstruction of identity, illness acceptance and coping with fibromyalgia in a positive way.

5.3 The narrative re-construction of life events and illness experiences (IV)

The third aim of the study was to examine how fibromyalgia patients with long illness history express, interpret and reconstruct their life events and their illness experiences in the form of a life story (Publication IV). Because the focus was on the structure of the life story, also the rhetorical means and subject positions of the participants were explored in the narrative analysis, in addition to comparison of the storylines of the life stories. Three model-narratives were identified from the data: narrative of mundane life, narrative of cumulative life and narrative of broken life. Furthermore, two participants took a subject position of 'healthy', thus creating a counter-narrative that challenges the view of fibromyalgia as a disabling condition that was expressed by all other interviewees.

'Narrative of mundane life' described a life with no dramatic turns, but rather an expected life course. In this narrative, fibromyalgia was accepted as a part of life, and it only disturbed life from time to time. All the women with 'mundane life' continued in a paid work role at the time of the interviews and had a positive view on functioning in the future. The 'narrative of cumulative life' was characterized by daily worries and cumulative vicissitudes that gradually led to a situation where one's resources were no longer adequate for retaining wellbeing. The onset of fibromyalgia was perceived as a result of long-term distress and uncontrollable fatigue. The work history during the past years was fragmented by sick leaves, and all but two of the women with 'cumulative life' were on temporary or permanent disability benefits at the time of the interviews.

The 'broken life narrative' was characterized by traumatic experiences that had changed the course of life permanently, such as death of a child or severe physical, sexual or mental violence. The onset of fibromyalgia was seen as an inevitable result of years of fatigue, worry and fear, in addition to physical or mental traumas caused by the unbearable life events. In many cases the traumatic events were silent secrets that were not shared with health professionals, let alone with friends or colleagues due to feelings of shame and guilt. All the women with a 'broken life' narrative were on permanent disability pension and most of them suffered from depression. The findings of the narrative analysis are summarized in Table 3.

TABLE 3 Summary of the findings of the narrative analysis.

	Mundane life	*Cumulative life*	*Broken life*	*Counter-narrative*
Life before illness	normal, safe, expected	cumulating daily hassles and worries	traumatic events	comparable with other participants
Perceived cause of the symptoms	overloading, sleeping problems	fatigue, distress	tension, fear, exhaustion, physical or/and mental traumas	injury, overload, tension
Metaphor for the rehabilitation course	source of information and support	time of one's own	escape	
Life after rehabilitation	return to work	fragmented work history	depression, increasing disability, exhaustion	full recovery
Perceived current functioning	maintaining paid work role with the help of adaptations at work and with social support	poor work ability/ disability	loss of control, lost work ability poor functioning	healthy

6 DISCUSSION

6.1 Methodological considerations

Before discussing the findings of the study, it is necessary to address some methodological considerations concerning the narrative approach that was applied in this doctoral thesis.

Qualitative research can be evaluated through transparency, reflexivity and transferability of the whole research process. In this context, reflexivity refers to systematic and continuous evaluation of the effect that the researcher has on the research process (Malterud 2001). In this doctoral study, the sampling process, collecting and analyzing the data – i.e. the audit trail – are described in detail to enhance the transparency and reflexivity of the research process and to provide possibilities to evaluate the authenticity and relevance of the findings. The author of this dissertation was responsible for carrying out all the interviews as well as for conducting the preliminary analysis. The fact that the participants voluntarily included extremely intimate experiences in their accounts suggests that the interviewer was perceived as reliable and easy to approach. The preliminary findings were discussed and elaborated with the co-authors to ensure validity.

For the narrative interviews, a purposive sample of twenty women was selected, aiming at maximal variation in regard to age, professional background and location in order to reach a rich variety of different experiences. The data may be skewed by the characteristics of the sample: the participants were all women and a majority of them were no longer in a paid work role. Life stories of men with fibromyalgia – and of aging women who manage to stay on at work – might bring new aspects into the discussion and should therefore be explored in the future. It is possible that in a bigger sample or in serial interviews some different or additional experiences could have emerged than those described in this study. Bearing in mind that narrative research aims at reaching a deep knowledge on the data through a thorough and versatile analysis (Curtis 2000; Malterud 2001), the amount and quality of the data in this study can be considered to be more than sufficient for the purposes of the study. Overcash (2003) pointed out that narrative method may not only answer the study question but also reveal additional aspects of life that were not identified as a primary focus of the research project. In the life stories of the present study, the participants included experiences such as domestic violence, financial problems or personal losses, thus creating forceful and evocative data for the analysis. The reminiscence and re-interpretation of these adverse experiences in relation to illness and functioning was acknowledged as an interesting and empowering experience by the interviewees.

In this study, possible memory bias was counteracted by the interview method, where the spontaneous narrative was deepened and completed by questions that emerged from the account. Nonetheless, it is recognized that personal narratives should not be seen as verification of facts; rather than that, narratives are interpretations of events that present the point of view of a particular narrator (Bruner 1991; Atkinson 2001). Although the results of a qualitative research cannot be generalized at large, it is possible to discuss the transferability of the results (Malterud 2001). Because a majority of patients with fibromyalgia are women in mid-life, it is possible that similar stories to those described in this study could be told by numerous fibromyalgia patients in other rehabilitation settings or other situations. Moreover, patients with other chronic conditions with obscure etiology and unpredictable illness course (e.g. chronic fatigue syndrome or chronic low back pain) might acknowledge some of the experiences described in this study. However, by taking a qualitative approach it is acknowledged that different interpretations of the data are possible and that both the interviewee and the interviewer have contributed to the nature and content of the data (Randall et al. 2006).

6.2 Perspectives on work ability and functioning in fibromyalgia

The results showed that work ability in fibromyalgia could not be captured in a single definition, but a spectrum of different ones (Publication I). Work ability of the participants had deteriorated over the years due to other health problems and aging. It is noteworthy that in all the narratives of this study health, illness and functioning were predominantly reflected through the ability or inability to work. This mirrors the importance of paid work role in Finnish women’s lives, not only from an economic standpoint, but also as a definer of identity (Publication IV). This is in accordance with Crooks (2007), who pointed out that women with fibromyalgia often experience a loss of identity due to work-related disability, which changes their life worlds and social networks significantly.

Confusion that was explicated by the participants of this study reflects the uncertainty that the onset of fluctuating symptoms caused. The participants were uncertain of the nature and severity of the symptoms, and worried about their work ability and future perspectives. Moreover, the invisibility of the symptoms caused problems in liability and legitimation of the illness in social contexts. The feeling of uncertainty has also been well established in earlier studies on fibromyalgia (Hallberg & Carlsson, 1998; Madden & Sim, 2006; Arnold et al. 2008).

In the narratives of the present study, loosing grip of working life did not happen suddenly, but gradually, over a long period of time. Some of the participants of the present study fell between the systems when paid work was no longer possible and disability benefits were rejected. Others would have been able to continue working but suitable work, considering the limitations they had, was not available. Moreover, in the data the experience 'over the edge of exhaustion' represented a situation where little or no work ability was left, and the patients were reluctantly drifting towards long-term work disability without having any control over the situation. Similar experiences of despair and giving up were described by Mannerkorpi et al. (1999) when they studied the daily life of patients with fibromyalgia.

The findings of the present study concord with and add knowledge to the results of Löfgren et al. (2006) who studied fibromyalgia patients who were still working 6-8 years after a rehabilitation course. They concluded that a low return-to-work rate demonstrates the difficulties fibromyalgia patients face in getting work after long or repeated sick-listings and lack of flexibility and support in the work place. Henriksson et al. (2005) pointed out that work rehabilitation should begin early so that preventive measures can be taken. However, in the narratives of the present study early rehabilitation interventions were either missing or started too late to retain participants' work ability. Kivimäki et al (2007) pointed out that a fluctuating level of disability is a key disadvantage related to fibromyalgia in the world of work, and that the risk for work absenteeism increases significantly if fibromyalgia is associated with another chronic health condition, e.g. osteoarthritis or depression. This tendency could also be seen in the descriptions of the changes of work ability in the present study.

The functional limitations described by the participants of this study are comparable to those described by earlier studies: difficulties in mobility, household tasks and in social life (Crooks 2007; Arnold et al. 2008; Lempp et al. 2009). Although numerous signs and symptoms of fibromyalgia were mentioned by the participants of this study, fatigue appeared to be the most disturbing symptom in regard to daily functioning and work ability (Publication II). Fatigue was perceived as a major cause of disability and distress, and it had consequences on every aspect of life. In the data of this study, psychosocial elements of fatigue were highlighted and in some of the life stories the experiences of pain, fatigue and depression seemed to be so tightly interwoven that they could be perceived as one entity instead of separate experiences. This is in concordance with the results of Hadlansmyth and Vowles (2009), who pointed out that depression and fatigue were significantly correlated to perceived disability, especially in terms of decreased psychosocial functioning. Moreover, in the modern society, it may be more socially acceptable to complain of fatigue and tiredness than depression or anxiety due to the heavy negative stigma that mental health problems have.

Bearing in mind that the average age of the participants of this study was 54 years and that they should on average be able to remain in paid work for nine more years before retirement, the impact of fibromyalgia on work ability in a long perspective seems to be detrimental. Based on the findings of the present study and those of earlier studies, it is justified to say that effective vocational rehabilitation interventions in the early stage of fibromyalgia are essential both from an individual and societal perspective to prevent spells of sick-listings and pre-term retirement among patients with fibromyalgia.

6.3 Perspectives on rehabilitation and peer support in fibromyalgia

Fibromyalgia has a major impact on people's lives, particularly on how they view themselves and how they think others view them. As Aldrich and Eccleston (2000) emphasize, what is important about chronic pain is not the pain itself, but the threat it causes to self-identity. According to Madden and Sim (2006), patients with fibromyalgia struggle to make sense of the fluctuating symptoms and give meanings to the diagnosis to enhance coping with the illness. Lack of knowledge about fibromyalgia may mean that the diagnosis as such offers neither a meaning nor a socially acceptable explanation and thus leaves the patient without acceptance and support in their social contexts (Madden & Sim 2006). Rehabilitation of fibromyalgia patients is generally aimed at responding to at least some of these challenges.

The participants of this study had participated in a multimodal rehabilitation course six to eight years prior to the interviews. The findings of the study highlight the importance of peer support in the rehabilitation process of patients with fibromyalgia (Publication III). Earlier studies on peer support in chronic pain conditions argue for substantial health benefits, especially in terms of increased self-efficacy and decreased pain and depression (Franks et al. 2004; Kukkurainen 2006; Lopez-Martinez et al. 2008). In the narratives of the present study, the women viewed the encounters with peers as a significant turning point in their lives; they were finally heard, believed and accepted. The interviewed women positioned themselves as 'hardworking' and 'work-oriented' to emphasize the contrast to the general attitude they confronted daily, in which their symptoms were ignored or belittled, and they were often labeled as 'work-dodgers' or 'whiners'. This finding is in accordance with Werner et al. (2004), who pointed out that in the medical discourse women with chronic pain are bound to repeatedly convince themselves, their colleagues and the professionals about the veracity and legitimacy of their symptoms.

In the present study, it was noticed that although the meanings ascribed to the rehabilitation course and peer support were mainly positive, not all patients were ready to discuss their problems or to receive support from their peers and thus implicitly showed a need for advanced, individual counseling instead of a group intervention. Similarly, according to Kukkurainen (2006), about 10% of the participants of the fibromyalgia–specific rehabilitation courses found the group intervention to be mentally burdensome and would have preferred a more individual approach. In the future, more attention needs to be paid to informing the patients about the goals and methods of the rehabilitation intervention as well as to exploration of individual paths in group interventions.

Suoyrjö et al. (2009) found that a fibromyalgia-specific rehabilitation course provided no benefit in comparison with a non-specific rehabilitation course in terms of occurrence of sick-leaves and disability pensions in a six-year follow-up. However, according to the results of the present study, the group-based fibromyalgia-specific rehabilitation course was in general found beneficial in a long perspective, although the need for updating the knowledge on fibromyalgia was apparent in the data. The seemingly obvious contradiction between these results can be explained in several ways. Firstly, since one motive for participation in the interviews of the present study was the wish to help others by sharing one's own experiences, it is possible that the participants did not want to bring adverse experiences of rehabilitation into discussion. Secondly, it is possible that people with negative experiences of group rehabilitation in general opted out of the follow-up study. Finally, also in the narratives of this study work histories of many participants were fragmented by sick leaves, and in several cases this had eventually lead to disability pension. However, the impact of the rehabilitation course and peer support was interpreted on a more psychological level: daring to be oneself, feeling a sense of community and enhancing empowerment through validation of experiences. A practical implication of the findings of the present study is that the psychosocial elements of rehabilitation, which can be provided and supported through a peer group, should be more purposively utilized and developed further in the rehabilitation interventions in the future.

6.4 Perspectives on life events

The rationale behind the narrative approach in health research lies fundamentally in the human desire to reach for coherence and continuity of self-perception (Hydén 1997). As Rimmon-Kenan (2002) expressed it: the narrators tend to emphasize elements of their past history that they did not stress before the illness in order to create new connections among events, and this is motivated by a conscious or unconscious desire to establish continuity between the present and past.

The narrative analysis revealed three model-narratives describing life and functioning before and after the onset of fibromyalgia and perceptions of current functioning and work ability. In addition to the model-narratives, a counter-narrative that questions the existence of fibromyalgia *per se* or as a chronic condition was identified. In the counter-narrative the women positioned themselves as ‘healthy’ or as ‘former fibromyalgia patients’. Beaton et al. (2001) studied what patients mean by recovery and found that recovery was interpreted as resolution of the disorder, as readjustment or as redefinition of self and health. Resolution of disorder was reflected either through possibilities to continue in one’s normal activities or through external evaluations, such as dosage of pain medication. Readjustment was explicated as learning to avoid situations that would aggravate the symptoms. Redefinition in turn included the idea of accepting the pain as a part of life. These elements may also be seen in the counter-narrative of this study, and it can be stated that the interpretation of the symptoms is largely affected by the individual situation and by the self-efficacy and coping style of each patient. In the future, it is important to explore the meanings and perceptions ascribed to recovery from fibromyalgia and whether or not they can be transformed or adjusted through rehabilitation interventions.

In the narrative reconstruction, the onset of widespread pain and fatigue was discussed in relation to other life events, perceived distress and physical burden. The rehabilitation course was seen metaphorically as a source of information, as time of one’s own or as an escape; again in relation to the life situation in general. It is noteworthy that although women with ‘broken lives’ referred to the rehabilitation course as an escape, and although the positive effects of rehabilitation could be wasted away in a couple of months due to the demanding life situation, it was nonetheless interpreted as a meaningful event in their illness process.

Hatcher and House (2003) emphasize that not only traumatic events but also daily hassles may have impact on the onset and maintenance of the symptoms of fibromyalgia. Also in this study, cumulation of daily vicissitudes and worries was perceived as a cause of stress and sleeping problems that eventually resulted in uncontrollable fatigue and agonizing pain. This finding is in line with Van Houdenhove, Neerincxk, Onghena et al. (2001) who pointed out that ‘action-proneness‘ may lead to overburdening of the body by musculoskeletal overuse or sleep deprivation, and that inability to set limits may lead to self-handicapping strategies, and could thus increase the susceptibility to fatigue, depression and widespread pain. Wilson et al. (2009) highlighted that the subgroups of fibromyalgia patients who report high levels of psychological or cognitive problems associated with moderate to high level of physical symptoms tend to use more health care services and to cope poorly with their symptoms. They concluded that these patients might benefit the most from psychological treatment aimed at improving coping skills. The findings of the present study support this view.

In the ‘broken life’ narratives the life course was permanently changed due to traumatic events and the onset of fibromyalgia was seen as an inevitable result of years of fatigue and fear. Although a narrative study cannot show causalities or the prevalence of violence or other traumatic events among fibromyalgia patients, it has the power to highlight the individual suffering behind these experiences. The experiences of mental, physical and sexual violence are in many cultures perceived as taboos that are not brought into discussion in social situations and are rarely shared even with professionals. Also Hänninen (2004) points out that in social storytelling settings narratives that are dramatic and coherent and that present the narrator in a favorable light are preferred, whereas problematic experiences that carry potential stigma are often kept private and remain untold. In this study, however, also experiences labeled with guilt, shame and fear were explicated by several participants, which can be seen as strength of the present study. Campbell (2002) emphasizes the fact that violence and abuse are risk factors for many health problems, notably depression, anxiety and chronic pain, but we are only beginning to understand the extent and nature of such risks. The present study accords with and expands the knowledge of the impact of traumatic life events reported in several quantitative studies on fibromyalgia and thus gives some novel perspectives to the ongoing general discussion on the etiology, development and maintenance of the symptoms of fibromyalgia (Anderberg et al. 2000; Campbell 2002; Kendall-Tackett et al. 2003; Haviland et al. 2010). To the best of the author’s knowledge, narrative analysis on experiences of life events of patients with fibromyalgia has not been reported earlier.

7 MAIN FINDINGS AND CONCLUSIONS

The main findings of the study can be summarized as follows:

- Work ability and functioning of the women with a long history of fibromyalgia had deteriorated substantially over the years. Work ability and functioning were not only challenged by the fibromyalgia symptoms but also by other health problems and psychosocial burdening caused by the life situation. Fatigue was described as the most disturbing symptom in regard to daily functioning and it had consequences on every aspect of life.

- Peer support was perceived as the most meaningful element of the rehabilitation. Meanings ascribed to peer support and rehabilitation were predominantly positive. However, it was also noticed that not all patients were ready to accept help and support from others. The long-term impact of peer support was expressed as daring to be oneself, as feeling a sense of community and as enhancing empowerment through validation of the illness experiences.

- Three different model-narratives and a counter narrative were revealed through the narrative emplotment. The main characteristics of the model narratives differ from each other in regard to life events before the symptoms, perceived cause of illness and rehabilitation metaphors as well as in terms of work ability after rehabilitation and perceived current functioning. However, fatigue, exhaustion and distress are described as a cause or a consequence of the illness in all of them. The counter narrative challenges these interpretations of life events. It also reflects the variety and fluctuation in symptom severity in fibromyalgia and highlights the possibility of recovery.

In conclusion, the results of the study show that severe pain and fatigue symptoms combined with a demanding life situation and aging may lead to substantial decrease of work ability and functioning in patients with a long history of fibromyalgia. It is essential that health professionals gain a deeper understanding on the multidimensional nature of the core symptoms of the patients with fibromyalgia in order to improve the quality of the health services. In health care and rehabilitation settings, it is important to recognize patients with a complex or traumatic life history, who may suffer from more severe psychological symptoms and may need a different rehabilitation approach compared to those with a less burdening background. However, it is equally important to acknowledge the diversity of life events and illness experiences associated with fibromyalgia in order to plan and implement more effective and individualized rehabilitation interventions. Furthermore, the reconstructed narratives presented in this study highlight the importance of storytelling in exploration of the possible causes and consequences of fibromyalgia.

YHTEENVETO

Naisten elämäntarinallisia kokemuksia fibromyalgiasta, toimintakyvystä ja elämäntapahtumista

Fibromyalgia on krooninen laaja-alainen kipuoireyhtymä, jonka syytä ei tunneta ja johon ei ole parantavaa hoitoa. Keskeisiä oireita kivun lisäksi ovat tavanomaisesta poikkeava väsymys ja unihäiriöt, mielialaoireet sekä kognitiivisiin toimintoihin liittyvät oireet, kuten keskittymis- ja muistivaikeudet. Valtaosa fibromyalgiaan sairastuneista on naisia ja tavallisimmin oireet alkavat 40 ikävuoden jälkeen. Eurooppalaisissa selvityksissä fibromyalgiaa on arvioitu esiintyvän 2-6.6 %:lla väestöstä ja esiintyvyyden on todettu lisääntyvän iän myötä. Eräiden tutkimusten mukaan 55–60 –vuotiailla naisilla esiintyvyys voi nousta jopa 8-10 %:iin. Moninaiset oireet haittaavat toiminta- ja työkykyä ja alentavat koettua elämänlaatua. Erityisesti fibromyalgia näyttäisi vaikeuttavan liikkumista ja tasapainoa, fyysisesti raskaista kodinhoito- tai työtehtävistä selviytymistä sekä sosiaalista kanssakäymistä. Tutkimusten mukaan fibromyalgiapotilaat kokevat elämänlaatunsa huonommaksi kuin esimerkiksi reumapotilaat, diabeetikot tai kroonisesta alaselkäkivusta kärsivät potilaat. Fibromyalgian hoidossa vahvinta näyttöä on osoitettu olevan hoito- ja kuntoutusmuodoista, joissa yksilöllisesti räätälöityyn lääkitykseen yhdistetään kohtuullisesti kuormittavaa aerobista liikuntaa tai voimaharjoittelua sekä sairauteen liittyvää tietoa ja hallintakeinojen kehittymistä tukevaa ohjausta.

Tämän tutkimuksen tarkoituksena oli selvittää pitkään fibromyalgiaa sairastaneiden henkilöiden näkökulmasta, millaisia vaikutuksia fibromyalgialla on heidän päivittäiseen elämäänsä ja toimintakykyynsä ja valottaa kuntoutuksen merkitystä heidän sairastumis-kuntoutumisprosessissaan useita vuosia fibromyalgiapotilaille suunnatun moniammatillisesti toteutetun kuntoutuskurssin jälkeen. Lisäksi haluttiin tarkastella, miten osallistujat tulkitsivat elämäntapahtumiaan ja sairauskokemuksiaan ja miten heidän kertomansa elämäntarinat rakentuivat. Tutkimus on osa Reumasäätiön sairaalassa vuonna 2007 käynnistettyä laajempaa seurantahanketta, jossa selvitetään fibromyalgian oireiden kehittymistä pitkällä aikavälillä, koettua toimintakykyä ja siinä tapahtuneita muutoksia sekä koettua terveyteen liittyvää elämänlaatua. Vuosina 1999–2001 Reumasäätiön sairaalassa järjestettyihin fibromyalgiakuntoutuskursseihin osallistuneista 169 henkilöstä lähes sata vastasi seurantakyselyyn ja 47 henkilöä antoi suostumuksensa myös haastattelututkimukseen osallistumiseen. Haastateltavien valinnassa käytettiin harkinnanvaraista otantaa, jonka avulla pyrittiin maksimaaliseen variaatioon eli tavoittamaan monipuolisesti erilaisia kokemuksia. Valintakriteereinä pidettiin ikää, ammatillista taustaa sekä asuinpaikkaa. Näin haastateltaviksi valikoitui 20 eri-ikäistä naista eri puolilta Suomea niin suurilta kuin pieniltäkin paikkakunnilta. Keski-iältään haastateltavat olivat 54-vuotiaita (vaihteluväli 34-65v) ja ammattitaustaltaan he edustivat suomalaisille naisille tyypillisiä työtehtäviä, kuten sosiaali- ja terveydenhuollon ja kasvatuksen ammatteja sekä erilaisia toimisto- ja teollisuustöitä.

Tutkimusaineisto kerättiin elämänkertahaastattelujen avulla. Aluksi haastateltavaa pyydettiin kertomaan vapaasti oma elämäntarinansa, jota täydennettiin haastattelun toisessa osiossa tarkentavilla ja laajentavilla kysymyksillä. Haastattelun lopuksi käytiin vielä keskustellen läpi haastateltavan esiintuomia kysymyksiä, kuten esimerkiksi fibromyalgian nykyisiä hoitosuosituksia tai kuntoutusmahdollisuuksia. Haastattelujen kesto vaihteli kahdesta neljään tuntiin ollen tavallisimmin noin kaksi ja puoli tuntia. Haastattelut tallennettiin digitaaliselle sanelimelle, josta ne litteroitiin sanasta sanaan tekstiksi.

Narratiivisessa eli kerronnallisessa tutkimuksessa mielenkiinnon kohteena on kokemus ja siitä kerrottu tarina, jonka kautta kokemusta rakennetaan, uudelleenarvioidaan ja reflektoidaan. Narratiivisuutta voidaan pitää väljähkönä metodisena viitekehyksenä, jonka puitteissa voidaan ajatella käytettävän lukuisia erilaisia aineiston analyysitapoja. Tässä tutkimuksessa aineisto analysoitiin vaiheittain. Ensimmäisessä vaiheessa analyysin painopiste oli tarinoiden sisällöissä; mistä haastateltavat puhuvat? Esiinnousseet teemat ja alateemat kirjattiin ylös jatkoanalyysejä varten. Toisessa analyysivaiheessa aineistosta pyrittiin erottelemaan episodeja, jotka sinällään kuvasivat jotakin tiettyä elämänvaihetta. Tunnistetut episodit järjestettiin kronologisesti, jotta voitiin tarkastella niiden välisiä yhteyksiä ja saatiin tarkennettua käsitystä kyseisen henkilön elämänkulusta. Analyysin kolmannessa vaiheessa painopiste oli tarinan rakenteessa; miten haastateltavat kertoivat elämäntarinansa? Aineistosta pyrittiin löytämään toistuvia juonirakenteita ja lisäksi tarkasteltiin haastateltavien käyttämiä retorisia keinoja sekä sitä, millaisesta näkökulmasta haastateltavat kulloinkin puhuvat.

Koetut toiminta- ja työkyvyn muutokset näyttäytyivät aineistossa toistuvina sairauslomina, vaikeuksina päivittäisistä toimista selviytymisessä ja ajoittaisena täydellisenä uupumisena sekä ennenaikaisena eläköitymisenä. Kahdestakymmenestä haastatellusta vain kuusi oli edelleen kokopäiväisesti työelämässä ja kaksi teki osa-aikatyötä. Vain yksi haastatelluista oli jäänyt työeläkkeelle ns. normaali-iässä. Loput haastatelluista olivat haastatteluhetkellä joko pitkäaikaisella sairauslomalla tai työkyvyttömyyseläkkeellä.

Toimintakyvyn heikentymistä kuvattiin ensinnäkin hämmennyksenä, joka liittyi oireiden alkamiseen ja siihen, että toistuvista lääkärissä käynneistä huolimatta oireille ei tahtonut löytyä syytä ja selitystä. Diagnoosin löytyminen koettiin helpotuksena ja se mahdollisti myös lisätiedon hankkimisen ja paransi mahdollisuuksia oireiden hallintaan ja tulkintaan. Toiseksi toimintakyvyn alenemista kuvattiin pärjäämisenä vaihtelevien oireiden kanssa, jolloin tilanteen koettiin olevan kutakuinkin hallinnassa. Kolmanneksi kuvattiin välitilaan jäämisen kokemusta, jossa haastateltavaa ei ollut voitu määritellä sen paremmin työkykyiseksi kuin työkyvyttömäksikään. Muutamissa tapauksissa tämä oli johtanut myös taloudellis-sosiaaliseen väliinputoamiseen, jolloin palkkatuloa ei ollut, sairauspäiväraha-aika oli käytetty eikä oikeutta työttömyysetuisuuksiin tai työkyvyttömyyseläkkeeseen ollut. Neljänneksi haastateltavat kuvasivat täydellisen uupumuksen kokemusta, jota edelsi sinnittely huonokuntoisena ”viimeisin voimin” työelämässä ja joka johti lopulta henkiseen ja fyysiseen romahtamiseen ja pitkäaikaiseen työkyvyttömyyteen. Tarinoissa oli silmiinpistävää ammatillisen kuntoutuksen toimenpiteiden puuttuminen tai myöhästyminen siten, että työkyky oli jo menetetty eikä paluu työelämään enää onnistunut.

Kaiken kaikkiaan väsymys näyttäytyi aineistossa hankalimpana ja vaikeimmin ennakoitavana oireena. Väsymystä kuvattiin paitsi unenpuutteena tai fyysisten voimien ehtymisenä, myös henkisenä väsymisenä, sosiaalisena jaksamattomuutena ja vetäytymisenä sekä kokonaisvaltaisena uupumisena. Aineistossa korostuivat väsymyksen psykososiaaliset piirteet. Fibromyalgiaa pitkään sairastaneilla naisilla väsymys, masennus ja kipu näyttäisivät kietoutuvan tiivisti yhdeksi kokonaisvaltaiseksi kokemukseksi, jossa niitä on vaikea erotella toisistaan. Aineiston perusteella näyttää myös mahdolliselta, että fibromyalgiapotilailla masennusoireet peittyvät väsymyksen taakse ja näin ollen masennuksen tunnistaminen ja asianmukaisen hoidon aloittaminen voivat viivästyä.

Tarkasteltaessa kuntoutuskurssiin liittyviä kokemuksia tämänhetkisestä näkökulmasta vertaistuki nousi kaikkein merkityksellisimmäksi elementiksi kuntoutuksessa. Useimmat haastateltavat olivat kärsineet erilaisista kipu- ja väsymysoireista jo vuosia, jotkut jopa vuosikymmeniä. Arkielämässään he olivat joutuneet usein selittämään sairauttaan ja puolustelemaan oireitaan, jotka eivät näy ulospäin. Monille kuntoutuskurssi oli ensimmäinen kohtaaminen samaa sairautta sairastavien kanssa ja erityisen merkityksellisenä pidettiin lupaa puhua ja jakaa kokemuksia fibromyalgiasta, sen oireista ja koetuista haitoista. Asiantuntijatiedon rinnalla toisilta kuntoutujilta saatu kokemuksellinen tieto nähtiin tärkeäksi. Vastavuoroisuus vertaistuen antamisessa ja saamisessa sekä aikaisemman ulkopuolisuuden kokemuksen muuttuminen joukkoonkuulumisen kokemukseksi korostuivat aineistossa. Vertaiskohtaaminen antoi myös mahdollisuuden vertailla ja punnita omaa tilannettaan toisten kanssa, mikä toi monille uusia näkökulmia oman toimintakyvyn arvioimiseen. Vertaistukeen liitetyt merkitykset olivat pääasiassa positiivisia: omana itsenä oleminen, kuuluminen joukkoon ja voimaantuminen kokemusten tunnustamisen ja vahvistamisen kautta. Monille motivaatio haastatteluun osallistumiseen oli halu auttaa toisia fibromyalgiapotilaita, jolloin on mahdollista että vertaistuen kielteisiä puolia ei tuotu haastattelussa esille. Tulosten perusteella voidaan kuitenkin päätellä, että vertaistuki koetaan merkityksellisenä vielä useita vuosia kuntoutuskurssin jälkeen etenkin oireiden oikeutuksen ja sitä kautta identiteetin uudelleenrakentumisen näkökulmasta. Kuntoutuksessa tulisikin jatkossa pohtia vertaistuen suunnitelmallisempaa ja tavoitteellisempaa käyttöä ja sitä, miten kuntoutujia valmennetaan kohtaamaan myös sairauden kielteisinä koettuja piirteitä.

Tutkimuksessa tunnistettiin juonirakenneanalyysin kautta kolme mallitarinatyyppiä sekä niiden vastakertomus. Tavanomaisen elämän tarinoissa elämänkulku eteni odotetusti ilman dramaattisia käänteitä tai odottamattomia tapahtumia. Kipu- ja väsymysoireet alkoivat vähitellen ilman suoranaista syytä, eikä niihin kiinnitetty aluksi huomiota, vaan niiden tulkittiin olevan seurausta fyysisestä kuormittumisesta, flunssasta tai muusta tavallisesta sairaudesta. Oireiden jatkuminen pidempään ja asteittainen paheneminen sai haastateltavat lopulta hakeutumaan hoitoon. Diagnoosin saaminen koettiin helpotuksena ja kuntoutuskurssille hakeutumisen motiivina kuvattiin halua saada lisää tietoa.

Toimintakyky koettiin vaihtelevaksi mutta oireiden koettiin olevan hallinnassa ja näissä tarinoissa tulevaisuus nähtiin valoisana. Kasautuvien huolien tarinoissa puolestaan elämänkulku muuttui erilaisten huolien ja vastoinkäymisten myötä. Fibromyalgian oireiden nähtiin olevan seurausta valvotuista öistä ja jatkuvasta pitkäaikaisesta stressistä, jolloin mahdollisuudet huolehtia omasta hyvinvoinnista heikentyivät. Kuntoutuskurssia kuvattiin oman ajan metaforalla. Kasautuvien huolien tarinassa toistuvat sairauslomat pirstaloivat työhistoriaa ja johtivat monissa tapauksissa työkyvyttömyys-eläkkeeseen ja heikentyneeseen toimintakykyyn arkielämässä.

Rikotun elämän tarinoita leimasi traumaattinen elämänkokemus, kuten läheisen kuolema tai koettu henkinen, fyysinen tai seksuaalinen väkivalta. Fibromyalgia oireiden kuvattiin olevan seurausta fyysisistä ja henkisistä vammoista, joita raskas elämäntilanne oli aiheuttanut. Kuntoutuskurssia kuvattiin pakometaforalla ja paluu takaisin ahdistavaan tilanteeseen kotona tai työssä kulutti voimavarat nopeasti loppuun. Rikotun elämän tarinoissa olivat tyypillisiä kokemukset täydellisestä uupumisesta ja vaikeasta masennuksesta tai koetusta ahdistuneisuudesta, jotka olivat johtaneet lopulta pysyvään työkyvyttömyyteen. Jopa tavanomaisista arkitoimista ja itsestä huolehtimisesta selviytyminen koettiin ajoittain haastavaksi. Nykyistä toimintakykyä luonnehdittiin hallitsemattomuuden kokemuksena sekä suhteessa omaan elämään että omaan kehoon ja mieleen.

Tutkijan rooli laadullisessa tutkimuksessa on paitsi analysoida aineistoa, myös osallistua sen tuottamiseen yhdessä haastateltavan kanssa. Tutkijan tuleekin tarkastella ja tiedostaa omia ennakkokäsityksiään käsiteltävissä olevista asioista voidakseen pystyä erottamaan ne haastateltavan esille tuomista ajatuksista. Tässä tutkimuksessa tutkimuksen kulku aineiston hankinnasta raportointiin saakka, on pyritty selostamaan tarkasti. Alkuperäisartikkeleihin on sisällytetty runsaasti sitaatteja haastatteluaineistosta, jotta lukijalla on mahdollisuus arvioida tehtyjen tulkintojen ja päätelmien paikkaansa pitävyyttä ja autenttisuutta. Kuten kaikessa laadullisessa tutkimuksessa on tässäkin tutkimuksessa kuitenkin todettava, että aineiston tulkintaan liittyy tutkijan subjektiivisuus ja että toiset tutkijat voisivat tehdä aineistosta erilaisia tulkintoja ja johtopäätöksiä.

Vaikka narratiivisen tutkimuksen tulokset eivät ole yleistettävissä laajempiin väestöryhmiin, voidaan pohtia, millä ehdoin tulokset ovat siirrettävissä niihin konteksteihin, joissa fibromyalgiaa sairastavat henkilöt toimivat. Tämän tutkimuksen haastateltavat olivat keski-ikäisiä naisia ja edustavat siten hyvin tyypillisiä fibromyalgiapotilaita, joten on todennäköistä että samantapaisia tarinoita voitaisiin kuulla muissakin toimintaympäristöissä. Samantyyppisten kokemusten ja tarinoiden kertautuminen aineistossa antaa viitteitä esimerkiksi sairauskokemusten jaettavuudesta. Traumaattisiin elämänkokemuksiin liittyy usein häpeää, pelkoa ja syyllisyyden tunteita. Tässä tutkimuksessa esiinnousseet tarinat saattavat rohkaista muitakin potilaita kertomaan vastaavanlaisista kokemuksista ja täten lisäämään tietoa esimerkiksi henkisen tai fyysisen väkivallan seurauksista. Narratiivisen tutkimuksen avulla voidaankin nostaa esiin kertojille merkityksellisiä näkökulmia ja antaa siten ääni vaietuille kokemuksille, joiden kautta on mahdollista ymmärtää sairastumiseen ja sairastamiseen liittyvää inhimillistä kärsimystä.

Tutkimuksen johtopäätöksenä voidaan todeta että vaikeat kipu- ja etenkin väsymysoireet yhdistettynä haastavaan elämäntilanteeseen ja ikääntymiseen saattavat johtaa työ- ja toimintakyvyn merkittävään alenemiseen fibromyalgiaa pitkään sairastaneilla naisilla. Terveydenhuollossa ja kuntoutuksessa on tärkeää tunnistaa fibromyalgiapotilaat, joilla on taustalla haasteellinen tai traumaattinen elämänhistoria, sillä he saattavat kärsiä psyykkisistä oireista ja saattavat siten tarvita erilaista hoitoa ja kuntoutusta kuin henkilöt, joilla on vähemmän kuormittava tausta. On kuitenkin yhtä tärkeää tunnistaa ja tunnustaa, että fibromyalgiaa sairastavien toimintakyky ja taustalla olevat elämäntapahtumat vaihtelevat laajasti. Kuntoutusinterventioissa tulisikin pyrkiä nykyistä paremmin huomioimaan osallistujien yksilölliset tarpeet ja voimavarat sekä käyttämään vertaistukea hyväksi tavoitteellisesti. Fibromyalgiaa sairastavien työterveyshuollossa ja ammatillisessa kuntoutuksessa on olennaista riittävän varhainen puuttuminen, jotta jatkossa vältyttäisiin pitkiltä sairauslomilta ja ennenaikaiselta eläköitymiseltä.

REFERENCES

Aaron LA & Buchwald D. Chronic diffuse musculoskeletal pain, fibromyalgia and co-morbid unexplained clinical conditions. Best Practice & Research in Clinical Rheumatology 2003; 17: 563-574.

Ablin J, Neumann L & Buskila D. Pathogenesis of fibromyalgia -A review. Joint Bone Spine 2008; 75: 273-279.

Aldrich S & Eccleston C. Making sense of everyday pain. Social Science & Medicine 2000; 50: 1631-1641.

Amir M, Kaplan Z, Neumann L, Sharabani R, Shani N & Buskila D. Posttraumatic stress disorder, tenderness and fibromyalgia. Journal of Psychosomatic Research 1997; 42: 607-616.

Amital D, Fostick L, Polliack ML, Segev S, Zohar J, Rubinow A & Amital H. Posttraumatic stress disorder, tenderness, and fibromyalgia syndrome: are they different entities? Journal of Psychosomatic Research 2006; 61: 663-669.

Anderberg UM, Marteinsdottir I, Theorell T & von Knorring L. The impact of life events in female patients with fibromyalgia and in female healthy controls. European Psychiatry 2000; 15: 295-301.

Arnold LM, Hudson JI, Hess EV, Ware AE, Fritz DA, Auchenbach MB Starck LO & Keck PE Jr. Family study of fibromyalgia. Arthritis & Rheumatism 2004; 50: 944-952.

Arnold LM, Crofford LJ, Mease PJ, Burgess SM, Palmer SC & Abetz LE. Patient perspectives on the impact of fibromyalgia. Patient Education and Counseling 2008; 73: 114-120.

Atkinson R. The life story interview. In J. Gubrium & J. Holstein (Eds.) Handbook of interview research: Context & Method. Thousand Oaks: Sage, 2001; 21-129.

Bailey BE, Freedenfeld RN, Sanford-Kiser R & Gatchell RJ. Lifetime physical and sexual abuse in chronic pain patients: psychosocial correlates and treatment outcomes. Disability and Rehabilitation 2003; 25: 331-342.

Baumgartner E, Finckh A, Cedraschi A & Vischer TL. A six -year prospective study of a cohort of patients with fibromyalgia. Annals of Rheumatic Disorders 2002; 61: 644-645.

Beaton DE, Tarasuk JN, Katz JN, Wright JG & Bombardier C. 'Are you better? ‘A qualitative study on meaning of recovery. Arthritis Care and Research 2001; 45: 270-279.

Becker B. Narratives of pain in later life and conventions of storytelling. Journal of Aging Studies 1999; 13: 73-87.

Bliddahl H & Danneskiold-Samsøe B. Chronic widespread pain in the spectrum of rheumatological diseases. Best Practice & Research in Clinical Rheumatology 2007; 21: 391-402.

Blyth FM, March LM, Nicholas MK & Cousins MJ. Chronic pain, work performance and litigation. Pain 2003; 103: 41-47.

Bradley LA & Alberts KA. Psychological and behavioural approaches to pain management for patients with rheumatic disease. Rheumatic Disease Clinics of North America 1999; 25: 215-232.

Branco J, Bannwarth B, Failde I, Carbonell J, Blotman F, Spaeth M , Saraiva F, Nacci F, Thomas E, Cauberé, LeLay K, Taieb C & Matucci-Cerinic M. Prevalence of Fibromyalgia: A Survey in Five European Countries. Seminars in Arthritis and Rheumatism 2010; 39: 448-453.

Brosseau L, Wells GA, Tugwell P, Egan M, Wilson KG, Dubouloz C-J, Casimiro L, Robinson VA, McGowan J, Busch A, Poitras S, Moldofsky H, Harth M, Finestone HM, Nielson W, Haines -Wangda A, Russel-Doreleyers M, Lambert K, Marshall AD & Veilleux L. Ottawa Panel Evidence-Based Clinical Practice Guidelines for Aerobic Fitness in the Management of Fibromyalgia. Physical Therapy 2008a; 88: 857-871.

Brosseau L, Wells GA, Tugwell P, Egan M, Wilson KG, Dubouloz C-J, Casimiro L, Robinson VA, McGowan J, Busch A, Poitras S, Moldofsky H, Harth M, Finestone HM, Nielson W, Haines -Wangda A, Russel-Doreleyers M, Lambert K, Marshall AD & Veilleux L. Ottawa Panel Evidence-Based Clinical Practice Guidelines for Strengthening Exercises in the Management of Fibromyalgia. Physical Therapy 2008b; 88: 873-885.

Bruner J. Life as Narrative. Social Research 2004; 71: 691-710.

Bruner J. The Narrative Construction of Reality. Critical Inquiry 1991;18: 1-21.

Burckhardt CS. Educating Patients: Self-Management Approaches. Disability and Rehabilitation 2005; 27: 703-709.

Burckhardt CS, Clark SR & Bennett CM. Fibromyalgia and quality of life: a comparative analysis. Journal of Rheumatology 1993; 20: 475-479.

Bury M. Chronic illness as biographical disruption. Sociology of Health and Illness 1982; 4: 167-182.

Buskila, D. Developments in the scientific and clinical understanding of fibromyalgia. Arthritis Research & Therapy 2009; 11: 1-8. (doi: 10.1186/ar2720).

Buskila, D. Genetics in Chronic Pain States. Best Practice & Research in Clinical Rheumatology 2007; 1: 535-554.

Buskila D, Neumann L, Alhoasle A & Abu-Shakra M. Fibromyalgia Syndrome in Men. Seminars in Arthritis and Rheumatism 2000; 30: 47-51.

Campbell JC. Health consequences of intimat partner violence. Lancet 2002; 359: 1331-1336.

Chaitow L. The history and definition of fibromyalgia. In L Chaitow (Ed.) Fibromyalgia Syndrome. A Practioner's Guide to Treatment. London: Churchill Livingstone, 2000: 1-20.

Cieza A, Stucki G, Weigl M, Kullmann L, Stoll T, Kamen L, Konstanjek N & Walsh N. ICF Core Sets for chronic widespread pain. Journal of Rehabilitation Medicine suppl. 2004; 44: 63-68.

Clauw DJ & Crofford LJ. Chronic widespread pain and fibromyalgia: what we know, and what we need to know. Best Practice & Research in Clinical Rheumatology 2003; 17: 685-701.

Cohen H, Neumann L, Haiman Y, Matar MA, Press J & Buskila D. Prevalence of Post-Traumatic Stress Disorder in Fibromyalgia Patients: Overlapping Syndromes or Post-Traumatic Fibromyalgia Syndrome? Seminars in Arthritis and Rheumatism 2002; 32: 38-50.

Crofford L. Pain management in fibromyalgia. Current Opinion in Rheumatology 2008; 20: 246-250.

Crooks VA. Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach. Social Science & Medicine 2007; 64: 577-588.

Curtis SG. Approaches to case selection in qualitative research; examples in the geography of health. Social Science & Medicine 2000; 50: 1001-1014.

Cöster L, Kendall S, Gerdle, Henriksson C, Henriksson KG & Bengtsson AS. Chronic widespread musculoskeletal pain- A comparison of those who meet criteria for fibromyalgia and those who do not. European Journal of Pain 2008; 12: 600-610.

Dadabhoy D, Crofford LJ, Spaeth M, Russel IJ & Clauw D. Evidence-based biomarkers for fibromyalgia syndrome. Arthritis Research & Therapy 2008; 10: 1-18 (doi:10.1186/ar2443).

de Gier M, Peters ML & Vlayen JW. Fear of pain, physical performance, and attentional processes in patients with fibromyalgia. Pain 2003; 104: 121-130.

Diatchenko L, Nackley AG, Slade GD, Fillingim RB & Maixner W. Idiopathic pain disorders - pathways of vulnerabity. Pain 2006; 123:226-230.

Dick BD, Verrier MJ, Harker KT & Rashiq S. 2008. Disruption of cognitive function in Fibromyalgia Syndrome. Pain 2006; 139: 610-616.

Fietta P, Fietta P & Manganelli P. Fibromyalgia and psychiatric disorders. Acta Bio Medica 2007; 78: 88-95.

Franks H, Cronan T & Oliver K. Social support in women with fibromyalgia: Is quality more important than quantity? Journal of Community Psychology 2004; 32: 425-438.

Fuller-Thomson E, Nimigon-Young J & Brennenstuhl S. Individuals with fibromyalgia and depression: findings from a nationally representative Canadian survey. Rheumatology International 2011 (e-published ahead of print).

Gallagher AM, Thomas JM, Hamilton WT & White PD. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. Journal of the Royal Society of Medicine 2004; 97: 571-575.

Garro LC. & Mattingly C. Narrative as Construct and Construction. In C. Mattingly, & LC. Garro: Narrative and the cultural construction of illness and healing. Berkeley: University of California Press, 2000: 1-49.

Geisser ME, Glass J, Rajcevska LD, Clauw DJ, Williams DA, Kileny PR & Gracely RH. Psychophysical Study of Auditory and Pressure Sensitivity in Patients with Fibromyalgia and Healthy Controls. Journal of Pain 2008; 9: 417-422.

Geisser ME, Gracely RH, Giesecke T, Petzke FW, Williams DA & Clauw DJ. The association between experimental and clinical pain measures among persons with fibromyalgia and chronic fatigue syndrome. European Journal of Pain 2007; 11: 202-207.

Giacomini M. Theory Matters in Qualitative Health Research. In I. Bourgeault, R. Dingwall & R. de Vries (Eds.) The SAGE Handbook of Qualitative Methods in Health Research. London: Sage, 2010: 125-156.

Giesecke T, Gracely RH, Williams DA, Geisser M, Petzke F & Clauw DJ. 2005. The relation between depression, clinical pain and experimental pain in a chronic pain cohort. Arthritis & Rheumatism 2010; 52: 1577-1584.

Glass JM, Park DC, Minear M & Crofford LJ. Memory beliefs and function in fibromyalgia patients. Journal of Psychosomatic Research 2005; 58: 263-269.

Goldberg RT, Pachas WN & Keith, D. Relationship between traumatic events in childhood and chronic pain. Disability and Rehabilitation 1999; 21: 23-30.

Goldberg R & Goldstein R. Comparison of chronic pain patients and controls on traumatic events in childhood. Disability and Rehabilitation 2000; 22: 756-763.

Gormsen L, Rosenberg R, Bach FW & Jensen TS. Depression, anxiety, health-related quality of life and pain in patients with chronic fibromyalgia and neuropathic pain. European Journal of Pain 2010; 127: 1- 8. (doi:10.1016/j.ejpain.2009.03.010).

Gracely RH, Petzke F, Wolfe JM & Clauw DJ. Functional magnetic resonance imaging evidence of augmented pain processing in patients with fibromyalgia. Arthritis & Rheumatism 2002; 46: 1333-1343.

Gupta A & Silman AJ. Psycological stress and fibromyalgia: a review of the evidence suggesting a neuroendocrine link. Arthritis Research & Therapy 2004, 6: 98-106.

Gustafsson M, Ekholm J & Nroman L. Effects of a multiprofessional rehabilitation program for fibromyalgia. A pilot study. Journal of Rehabilitation Medicine 2002; 34: 119-127.

Haack M & Mullington JM. Sustained sleep restriction reduces emotional and physical well-being. Pain 2005; 119: 56-64.

Hadlansmyth K & Vowles KE. Does depression mediate the regulation between fatigue severity and disability in chronic fatigue syndrome sufferers? Journal of Psychosomatic Research 2009; 66: 31-35.

Hallberg L & Carlsson SG. Psychosocial Vulnerability and Maintaining Forces Related to Fibromyalgia: In-depht Interviews with Twenty-two Female Patients. Scandinavian Journal of Caring Sciences 1998; 12: 95-103.

Hatcher S & House A. Life events, difficulties and dilemmas in the onset of chronic fatigue syndrome: a case- control study. Psychological Medicine 2003, 33: 1185-1192.

Haviland MG, Morton KR, Oda K & Fraser GE. Traumatic experiences, major life stressors, and self-reporting a physician-given fibromyalgia diagnosis. Psychiatry Research 2010; 177: 335-341.

Heikkinen H. Whatever is narrative research? In R. Huttunen, H. Heikkinen & L. Syrjälä (Eds.) Narrative research: voices of teachers and philosophers. Jyväskylä: Jyväskylän yliopisto, 2002.

Henriksson C, Liedberg G & Gerdle B. Women with fibromyalgia: Work and rehabilitation. Disability and Rehabilitation 2005; 27: 685-695.

Hieblinger R, Coenen M, Stucki G, Winkelmann A & Cieza A. Validation of the International Classification of Functioning, Disability and Health Core Set for Chronic Widespread Pain from the Perspective of Fibromyalgia Patients. Arthritis Research & Therapy 2009; 11: R67 (doi:10.1186/ar2696)

Hirsh AT, Waxenberg LB, Atchinson JW, Gremillion HA & Robinson ME. Evidence for Sex Differences in the Relationships of Pain, Mood and Disability. The Journal of Pain 2006; 7: 592-601.

Hydén L-C. Illness and Narrative. Sociology of Health and Illness 1997; 19: 48-69.

Hydén M. 'I Must Have Been an Idiot to Let it Go On': Agency and Positioning in Battered Women's Leaving. Feminism & Psychology 2005; 15. 169-188.

Häkkinen K, Pakarinen A, Hannonen P, Häkkinen A, Airaksinen O, Valkeinen H & Alen M. Effects of strength training on muscle strength, cross-sectional area, maximal elektromyographic activity, and serum hormones in premenopausal women with fibromyalgia. Journal of Rheumatology 2002; 29: 1287-1295.

Hänninen V. A model of narrative circulation. Narrative Inquiry 2004; 14: 69-85.

Hänninen V & Valkonen J. Tarinat, sairaudet ja kuntoutuminen. In V. Hänninen & J. Valkonen (Eds.), Kunnon tarinoita. Tarinallinen näkökulma kuntoutukseen. Helsinki: Kuntoutussäätiö, 1998: 3-20.

Häuser W, Eich W, Herrmann M, Nutzinger DM, Schiltenwolf M, Henningsen PE. Fibromyalgia Syndrome. Classification, Diagnosis and Treatment. Deutsches Ärzteblatt International 2009; 106: 383-391.

Häuser W, Klose P, Langhorst J, Moradi B, Stainbach M, Schiltenwolf M & Busch A. Efficacy of different types of aerobic exercise in fibromyalgia syndrome: a systematic review and meta-analysis of randomised controlled trials. Arthritis Research & Therapy 2010; 12:R79.

Häuser W, Thieme K & Turk D. Guideline on the management of fibromyalgia syndrome -A systematic review. European Journal of Pain 2010; 14: 5-10.

Imbierowicz K & Egle UT. Childhood adversities in patients with fibromyalgia and somatoform pain disorder. European Journal of Pain 2003, 7: 113-119.

Johansson EE, Hamberg K, Westman G & Lindgren G. The meanings of pain: an exploration of women's descriptions of symptoms. Social Science & Medicine 1999; 48: 1791-1802.

Jones GT, Power C & Macfarlane GJ. Adverse events in childhood and chronic widepread pain in adult life: results from the 1958 British Birth Cohort Study. Pain 2009; 143: 92-96.

Jones GT, Silman AJ & Macfarlane GJ. Predicting the Onset of Widespread Body Pain Among Children. Arthritis & Rheumatism 2003; 48: 2615-2621.

Jones GT, Silman AJ, Power C & Macfarlane GJ. Are common symptoms in childhood associated with chronic widespread body pain in adulthood? Results from the 1958 British Birth Cohort Study. Arthritis & Rheumatism 2007; 56: 1669-1675.

Jones J, Rutledge DN, Jones K, Matallana L & Rooks DS. Self –assessed physical function levels of women with fibromyalgia. A National Survey. Women's Health Issues 2008; 18: 406-412.

Jones KD, Horak FB, Stone Winters K, Morea JM & Bennett RM. Fibromyalgia is Associated with Impaired Balance and Falls. Journal in Rheumatology 2009; 15: 15-21.

Julien N, Goffaux P, Arsenault P & Marchand S. Widespread pain is related to a deficit of endogeous pain inhibition. Pain 2005; 114: 295-302.

Katz RS, Wolfe F & Michaud K. Fibromyalgia diagnosis. A comparison of Clinical survey and American College of Rheumatology Criteria. Arthritis & Rheumatism 2006; 54: 169-176.

Keefe FJ, Rumble ME, Scipio CC, Giordano LA & Perri LM.. Psychologiacal Aspects of Persistent Pain: Current State of the Science. The Journal of Pain 2004; 5: 195-211.

Kendall-Tackett K, Marshall R & Ness K. Chronic pain syndromes and Violence against Women. Women & Therapy 2003; 26: 45-56.

Keogh E, McCracken LM & Eccleston C. Gender moderates the association between depression and disability in chronic pain patients. European Journal of Pain 2006; 10: 413-422.

Kingsley JD, Panton LB, Toole T, Sirithienthad P, Mathis R & McMillan V. The Effects of a 12-Week Strength-Training Program on Strength and Functionality in Women with Fibromyalgia. Archives in Physical Medicine and Rehabilitation 2005; 86: 1713-1721.

Kivimäki M, Leino-Arjas P, Kaila-Kangas L, Virtanen M, Elovainio M, Puttonen S, Keltinkangas-Järvinen L, Pentti J & Vahtera J. Increased absence due to sickness among employees with fibromyalgia. Annals of the Rheumatic Diseases 2007; 66: 65-69.

Kleinman N, Harnett J, Melkonian A, Lynch W, Kaplan-Mahlis B & Silverman S. Burden of fibromyalgia and comparisons with osteoarthritis in the workforce. Journal of Occupational and Environmental Medicine 2009. 51: 1384-1393.

Kukkurainen ML. Fibromyalgiaa sairastavien koherenssintunne, sosiaalinen tuki ja elämänlaatu. Dissertation. Oulu: University of Oulu. 2006.

Labov W & Waletsky J. Narrative Analysis: Oral Versions of Personal Experience [reprint from 1967]. In C. Bratt Paulston & G. Tucker (Eds.) Sociolinguistics: the Essential Readings. Oxford: Blackwell, 2003: 74-104.

Lampe A, Doering S, Rumpold G, Sölder E, Krismer M, Kantner-Rumplmaier W, Scubert C & Söllner W. Chronic pain syndromes and their relation to childhood abuse and stressfull life events. Journal of Psychosomatic Research 2003; 54: 361-367.

Laursen B, Bajaj P, Olesen AS, Delmar C & Arendt-Nielsen L. Health related quality of life and quantitative pain measurements in females with chronic non-malignant pain. European Journal of Pain 2005; 9: 267-275.

Leavitt F & Katz RS. Distraction as a key determinant of impaired memory in patients with Fibromyalgia. Journal of Rheumatology 2006; 33: 127-132.

Lempp HK, Hatch SL, Carville SF & Choy EH. Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study. BMC Musculoskeletal Disorders 2009; 10: 1-11 (doi: 10.1186/1471-2474-10-124).

Lemstra M & Olszynski WP. The Effectiveness of Multidisciplinary Rehabilitation in the Treatment of Fibromyalgia. Clinical Journal of Pain 2005; 21: 166-174.

Liedberg GM, Burckhardt CS & Henriksson CM. Young women with fibromyalgia in the United States and Sweden: Perceived difficulties during the first year after diagnosis. Disability and Rehabilitation 2006; 28: 1177-1184.

Lindeman S, Hämäläinen J, Isometsä E, Kaprio J, Poikolainen K, Heikkinen M & Aro H. The 12-month prevalence and risk factors for major depressive episode in Finland: representative sample of 5993 adults. Acta Psychiatrica Scandinavica 2001; 102: 178-184.

Lindgren H & Bergman S. Chronic musculoskeletal pain predicted hospitalisation due to serious medical conditions in a 10 year follow up study. BMC Musculoskeletal Disorders 2010; 11: 127 (doi:10.1186/1471-2474-11-127).

Lopez-Martinez A., Estevez-Zarazaga R & Ramirez-Maestre P. Perceived social support and coping responses are independent variables explaining pain adjustment among chronic pain patients. The Journal of Pain 2008; 9: 373-379.

Löfgren M, Ekholm J & Öhman A. 'A constant struggle': successful strategies of women in work despite fibromyalgia. Disability and Rehabilitation 2006; 28: 447- 455.

Macfarlane GJ, McBeth J & Silman AJ. Widespread body pain and mortality: prospective population based study. British Medical Journal 2001; 323: 662-665.

Madden S & Sim J. Creating meaning in fibromyalgia syndrome. Social Science & Medicine 2006; 63: 2962-2973.

Malterud K. Qualitative research:standards, challenges and guidelines. The Lancet 2001; 358: 483-488.

Mannerkorpi K, Ahlmén M & Ekdahl C. Six and 24 months follow-up of pool exercise therapy and education for patients with fibromyalgia. Scandinavian Journal of Rheumatology 2002; 31: 306-310.

Mannerkorpi K, Nyberg B, Ahlmén M & Ekdahl C. Pool exercise combined with an education program for patients with fibromyalgia syndrome. Journal of Rheumatology 2000; 27: 2473-2481.

Mannerkorpi K & Iversen M. Physical exercise in fibromyalgia and related syndromes. Best Practice & Research Clinical Rheumatology 2003; 17: 629-47.

Mannerkorpi K, Kroksmark T & Ekdahl C. How patients with fibromyalgia experience their symptoms in everyday life. Physiotherapy Research International 1999; 4: 110-122.

Mannerkorpi K, Nordeman L, Cider Å & Jonsson G. Does moderat-to-high intensity Nordic walking imporve functional capacity and pain in fibromyalgia? A prospective randomized controlled trial. Arthritis Research & Therapy 2010; 12: R189.

Markkula R, Järvinen P, Leino-Arjas P, Koskenvuo M, Kalso E & Kaprio J. Clustering of symptoms associated with fibromyalgia in Finnish Twin Cohort. European Journal of Pain 2009; 13:744-750.

McBeth J, Silman AJ , Gupta A, Chiu YH, Ray D, Morris R, Dickens C, King Y & Macfarlane GJ. Moderation of Psychosocial risk Factors Through Dysfunction of the Hypothalamic-Pituitary-Adrenal Stress Axis in the Onset of Chronic Widespread Musculoskeletal Pain. Arthritis & Rheumatism 2007; 56: 360-371.

McBeth J, Symmons DP, Silman AJ, Allison T, Webb R & Macfarlane GJ. Musculoskeletal pain is associated with a long-term increased risk of cancer and cardiovascular-related mortality. Rheumatology 2009; 48: 74-77. McFarlane AC. Stress-related musculoskeletal pain. Best Practice & Research Clinical Rheumatology 2007; 21: 549-565.

Mengshoel AM & Heggen K. Recovery from fibromyalgia - previous patients own experiences. Disability and Rehabilitation 2004; 26: 46-53.

Mikkelsson M, El-Metwally A, Kautiainen H, Auvinen A, Macfarlane GJ & Salminen JJ. Onset, prognosis and risk factors for widespread pain in schoolchildren: A prospective 4-year follow-up study. Pain 2008; 138: 681–687.

Moldofsky H. The significance of the sleeping-waking brain for the understanding of widespread musculoskeletal pain and fatigue in fibromyalgia syndrome and allied syndromes. Joint Bone Spine 2008; 75: 397-402.

Mäntyselkä P, Kumpusalo E, Ahonen R, Kumpusalo A, Kauhanen J, Viinamäki H, Halonen P & Takala J. Pain as a reason to visit the doctor: a study in Finnish primary health care. Pain 2001; 89: 175-180.

Nicassio PM, Moxham EG, Schuman CE & Gevirtz RN. The contribution of pain, reported sleep quality, and depressive symptoms to fatigue in fibromyalgia. Pain 2002; 100: 271-279.

Nicholl BI, Macfarlane GJ, Davies KA, Morris R, Dickens C & McBeth J. Premorbid psychosocial factors are associate with poor health-related quality of life in subjects with new onset of chronic widespread pain – Results from the EPIFUND study. Pain 2009; 141: 119-126.

Ofluoglu D, Berker N, Güven Z, Canbulat N, Yilmaz IT & Kayhan Ö. Quality of life in patients with fibromyalgia syndrome and rheumatoid arthritis. Clinical Rheumatology 2005; 24: 490-492.

Overcash JA. Narrative research: a review of methodology and relevance to clinical practice. Critical Reviews in Oncology/Hematology 2003; 48: 179-184.

Papageorgiou AC, Silman AJ & Macfarlane GJ. Chronic widespread pain in the population: a seven year follow up study. Annals of the Rheumatic Diseases 2003; 61: 1071-1074.

Park DC, Glass FM, Minear M & Crofford LJ. Cognitive function in fibromyalgia patients. Arthritis & Rheumatism 2001; 44: 2125-2133.

Parrish BP, Zautra AJ & Davis MC. The Role of Positive and Negative Interpersonal Events on Daily Fatigue in Women with Fibromyalgia, Rheumatoid Arthritis and Osteoarthritis. Health Psychology 2008; 27: 694-702.

Pirttilä T & Nybo T. Kipu ja kognitio. Duodecim 2004; 120: 199-305.

Polkinghorne DE. Narrative Knowing and the Study of Lives. In J. Birren (Ed.) Aging and biography: explorations in adult development New York: Springer, 1996: 77-99.

Rahinantti P. Psyykkiset tekijät fibromyalgiassa. Dissertation. Kuopio: University of Kuopio, 1998.

Randall WL, Prior SM & Skarborn M. How listeners shape what tellers tell. Patterns of interaction in life story interviews and their impact on reminiscencs by elderly interviewees. Journal of Aging Studies 2006; 20: 381-396.

Reisine S, Fifield J, Walsh S & Dauser Forrest D. Employment and Health Status Changes Among Women With Fibromyalgia: A Five Year Study. Arthritis & Rheumatism 2008; 59: 1735-1741.

Ricoeur P. Time and Narrative I. Chicago. The Univesity of Chigago Press. 1984

Ricoeur P. Time and Narrative III. Chicago: The University of Chicago Press. 1987.

Ricoeur P. Oneself as Another. Chicago: Chicago University Press.1992.

Riessman, C. Analysis of personal narratives. In J. Gubrium, & J. Holstein, Handbook of interview research: context & methods. Thousand Oaks: Sage, 2001; 695-707.

Riessman C & Speedy J. Narrative inquiry in the psychotherapy professions. In D. Clandinin (Ed.) Handbook of narrative inquiry. London: Sage, 2007: 695-707.

Rimmon-Kenan S. The Story of 'I': Illness and Narrative Identity. Narrative 2002; 10: 9-27.

Rosenthal G. The healing effects of storytelling: on the conditions of curative storytelling in the context of research and counselling. Qualitative Inquiry 2003; 9, 915-933.

Ryan S, Hill J, Thwaites C & Dawes P. Assessing the effect of fibromyalgia on patients' sexual activity. Nursing Standard 2008; 23: 35-41.

Råheim M & Håland W. Lived Experience of Chronic Pain and Fibromyalgia: Women's Stories From Daily Life. Qualitative Health Research 2006; 16: 741-761.

Sarzi-Puttini P, Buskila D, Carrabba M, Doria A & Atzeni F. Treatment Strategy in Fibromyalgia: Where are we now? Seminars in Arthritis and Rheumatism 2008; 37: 353-365.

Schirm V. Quality of life. In P. Larsen, & I. Lubkin (Eds.) Chronic Ilness. Impact and Intervention. London: Jones & Bartlett Publishers, 2009: 139-160.

Schwandt TA. Three Epistemiological Stances for Qualitative Inquiry. Interpretivism, Hermeneutics and Social Constructionism. In N.Denzin & Y. Lincoln Handbook of Qualitative Research. Thousand Oaks: Sage, 2000: 189-213.

Sim J & Madden S. Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. Social Science & Medicine 2008; 67: 57-67.

Sintonen H. The 15D instrument of health-related quality of life. Properties and applications. Annals of Medicine 2001; 33: 328-226.

Smith AA. Intimacy and Family Relationship of Women with Chronic Pain. Pain Management Nursing 2003; 4: 134-142.

Sonnenschein M, Mommersteeg P, Houtveen J, Sorbi M, Schaufeli W & van Doornen L. Exhaustion and endocrine function in clinical burnout. An in-depth study using the experience sampling method. Biological Psychiatry 2007; 745: 176-84.

Sowden M, Hatch A, Gray SE & Coombs J. Can four key psychosocial risk factors for chronic pain and disability (Yellow Flags) be modified by a pain management programme? A pilot study. Physiotherapy 2006; 92: 43-49.

Spaeth, M. Epidemiology, costs, and the economic burden of fibromyalgia (Editorial). Arthritis Researvch & Therapy 2009; 11: 1-2.

Suoyrjö H, Oksanen T, Hinkka K, Pentti J, Kivimäki M, Klaukka T & Vahtera J. A comparison of two multidisciplinary inpatient rehabilitation programmes for fibromyalgia: a register linkage study on work disability. Journal of Rehabilitation Medicine 2009; 41: 66-72.

Söderberg S, Lundman B & Norberg A. Struggling for dignity: the meaning of womens experiencies of living with fibromyalgia. Qualitative Health Research 1999, 9: 575-587.

Söderberg S, Lundman B & Norberg A. The meaning of fatigue and tiredness as narrated by women with fibromyalgia and healthy women. Journal of Clinical Nursing 2002, 11: 247-255.

Taylor RR & Jason LA. Chronic fatigue, abuse-related traumatization, and psychiatric disorders in a community-based sample. Social Science & Medicine 2002; 55:247-256.

Theadom A & Cropley M. Dysfunctional beliefs and sleep disturbances in fibromyalgia. Sleep Medicine 2008; 9: 376-381.

Theadom A, Cropley M & Humphrey K-L. Exploring the role of sleep and coping in quality of life in fibromyalgia. Journal of Psychosomatic Research 2007; 62: 145-151.

Thieme K, Turk DC & Flor H. Comorbid Depression and Anxiety in Fibromyalgia Syndrome: Relationship to Somatic and Psychosocial Variables. Psychosomatic Medicine 2004; 66: 837-844.

Valkeinen H. Physical Fitness, Pain and Fatigue in Postmenopausal Women with Fibromyalgia. Dissertation. Jyväskylä: University of Jyväskylä, 2007.

Valkeinen H, Häkkinen A, Hannonen P, Häkkinen K & Alén M. Acute Heavy Resistance Exercise-induced Pain and Neuromuscular Fatigue in Elderly Women With Fibromyalgia and in Healthy Controls. Arthritis & Rheumatism 2006; 54: 1334-1339.

Walker J G & Littlejohn GO. Measuring quality of life in rheumatic conditions. Clinical Rheumatology 2007; 26: 671-673.

Van Houdenhove B, Neerinckx E, Lysens R, Vertommen H, Van Houdenhove L, Onghena P, Westhovens R & D'Hooghe M-B. Victimization in Chronic Fatigue syndrome and Fibromyalgia in Tertiary Care. Psychosomatics 2001; 42: 21-28.

Van Houdenhove B, Neerincxk E, Onghena P, Lysens R & Vertommen H. Premorbid "overactive" lifestyle in chronic fatigue syndrome and fibromyalgia. An etiological factor or proof of good citizenship. Journal of Psychosomatic Research 2001; 51: 571-576.

van Ittersum MW, van Wilgen CP, Hilberdink WK, Groothoff JW & van der Schans CP. Illness Perceptions in Patients with Fibromyalgia. Patient Education and Counseling 2009; 74: 53-60.

van Wilgen C, van Ittersum MW, Kaptein AA & van Wijhe M. Illness Perception in Patients with Fibromyalgia and Their Relation to Quality of Life and Catastrophizing. Arthritis & Rheumatism 2008; 59: 3618-3626.

Ware J & Sherbourne C. The MOS 36-item short-form health survey (SF-36). Conceptual framework and item selection. Medical Care 1992; 30: 473-483.

Watson NF, Buchwald D, Goldberg J, Noonan C & Ellenbogen RG. Neurologic Signs and Symptoms in Fibromyalgia. Arthritis & Rheumatism 2009; 60: 2839-2844.

Wengraf T. Qualitative research interviewing: biographic narrative and semistructured methods. London: Sage, 2001.

Verbunt J, Pernot D & Smeets R (2008). Disability and quality of life in patients with fibromyalgia. BMC Health and Quality of Life Outcomes 2008; 6: 1-8 (doi:10.1186/1477-7525-6-8).

Werner A, Widding Isaksen L & Malterud K. 'I am not the kind of woman who complains of everything': Illnes stories on self and shame in women with chronic pain. Social Science & Medicine 2004; 59: 1035-1045.

White KP, Speechley M, Harth M & Ostbye T. Comparing self-reported function and work disability in 100 community cases of fibromyalgia syndrome versus controls in London, Ontario. Arthritis & Rheumatism 1999; 42: 76-83.

Williams DA. Psychological and behavioural therpies in fibromyalgia and related syndromes. Best Practice & Research Clinical Rheumatology 2003; 17: 640-665.

Williams DA & Clauw DJ. Understanding Fibromyalgia: Lessons from the Broader Pain Research Community. The Journal of Pain 2009; 10; 8: 777-791.

Wilson HD, Robinson JP & Turk DC. Toward the Identification of Symptom Patterns in People with Fibromyalgia. Arthritis & Rheumatism 2009: 61; 527-534.

Wolfe, F. New American College of Rheumatology Criteria for Fibromyalgia: A Twenty Year Journey. (Editorial) Arthritis Care & Research 2010, 62: 583-584.

Wolfe F, Clauw D, Fitzcharles M, Goldenberg D, Katz R, Mease P, Russel AS, Russel IJ, Winfield JB & Yunus MB. The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom severity. Arthritis Care & Research 2010; 62: 600-610.

Wolfe F, Smythe HA, Yunus MB, Bennett RM, Bombardier C, Goldenberg DL, Tugwell P, Campbell SM, Abeles M, Clark P, Fam AG, Farber SJ, Fiechtner J Franklin CM, Gatter RA, Hamaty D, Lessard J, Lichtbroun AS, Masi AT, McCain GA, Reynolds WJ, Romano TJ, Russell IJ, Sheon RP. The American College of Rheumatology 1990 Criteria for the classification of fibromyalgia. Arthritis & Rheumatism 1990; 33: 160-172.

Wolfe F, Michaud K, Li T & Katz RS. EQ-5D and SF-36 Quality of life measures in systemic lupus erythematosus: comparisons with rheumatoid arthritis, noninflammatory rheumatic disorders, and fibromyalgia. Journal of Rheumatology 2010; 37: 296-304.

Vollenstand NK & Mengshoel AM. Relationships between neuromuscular functioning, disability and pain in fibromyalgia. Disability and Rehabilitation 2005; 27: 667- 673.

Yunus MB. Fibromyalgia and Overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes. Seminars in Arthritis and Rheumatism 2007; 36: 339-356.

Yunus MB. (2008). Central Sensitivity Syndromes: a new paradigm and Group Nosology for Fibromyalgia and Overlapping Conditions, and the related issue of Disease versus Illness. Seminars in Arthritis and Rheumatism 2008; 37: 339-352.

Zautra AJ, Fasman R, Parish BP & Davis MC. Daily fatigue in women with osteoarthritis, rheumatoid arthritis and fibromyalgia. Pain 2007; 128: 128-135.

Appendix 1

Preliminary diagnostic criteria for fibromyalgia ACR-2010 (modified from Wolfe et al. 2010).

Criterion	*Definition*
Widespread pain index **WPI (0-19)**	The number of areas in which the patient has had pain over the last week. Score between 0 and 19. Shoulder girdle left / right Hip left / right Jaw left / right Upper arm left / right Lower arm left/ right Upper leg left/ right Lower leg left/ right Neck Upper back Lower back
Symptom severity scale **SS- score (0-12)**	The SS scale score is the sum of the 3 symptoms plus the extent of somatic symptoms in general. Final SS- score is between 0-12 ***Fatigue, waking unfreshened, cognitive symptoms;*** for each of the three symptoms above indicate the level of severity over the past week following the scale: • 0=no problems • 1= slight problems, generally mild or intermittent • 2= moderate, considerable problems, often present an / or at moderate level • 3= severe; pervasive, continuous, life disturbing problems ***Somatic symptom severity * ;*** indicate whether the patient has • 0= no somatic symptoms • 1= few somatic symptoms • 2=a moderate number of symptoms • 3= a great deal of symptoms
Diagnostic criteria	1) WPI at least 7 and SS-score at least 5 or WPI 3-6 and SS-score at least 9 or more 2) symptoms have been at similar level for at least 3 months 3) the patient has no other disorder that would otherwise explain the symptoms

*= muscle pain, irritable bowel syndrome, fatigue/ tiredness, thinking or remembering problem, muscle weakness, headache, pain / cramps in the abdomen, numbness / tingling, dizziness, insomnia, depression, constipation, pain in the upper abdomen, nausea, nervousness, chest pain, blurred vision, fever, diarrhea, dry mouth, itching, wheezing, Reynaud's phenomenon, hives/ welts, ringing in the ears, vomiting, heartburn, oral ulcers, loss/ change of taste, seizures, dry eyes, shortness of breath, loss of appetite, hearing difficulties, easy bruising, hair loss, frequent urination, painful urination and bladder spasms

ORIGINAL PAPERS

I

WOMEN’S NARRATIVES ON EXPERIENCES OF WORK ABILITY AND FUNCTIONING IN FIBROMYALGIA

by

Sallinen M, Kukkurainen ML, Peltokallio L & Mikkelsson M, 2011

Musculoskeletal Care 8; 18-26

Reproduced with kind permission by John Wiley & Sons, Ltd

RESEARCH ARTICLE

Women's Narratives on Experiences of Work Ability and Functioning in Fibromyalgia

Merja Sallinen[1],*, Marja Leena Kukkurainen[2], Liisa Peltokallio[3] & Marja Mikkelsson[4]

[1]Rheumatism Foundation Hospital, Heinola, and Satakunta University of Applied Sciences, Pori, Finland
[2]Rheumatism Foundation Hospital, Heinola, Finland
[3]Department of Health Sciences, Faculty of Sport and Health Sciences, Jyväskylä University, Jyväskylä, Finland
[4]Päijät-Häme Central Hospital, Lahti, Finland, Päijät-Häme Social and Health Care Group

Abstract

Background. Fibromyalgia is a significant health problem for women of working age. However, little is known about the long-term effects of fibromyalgia in everyday life or on work ability. **Methods.** A narrative interview study was conducted to explore the experiences of work ability and functioning of patients with a long history of fibromyalgia. Twenty women, aged 34–65 years, were purposively chosen for the interviews, to reach a wide range of patients with different social and professional backgrounds. **Results.** Four types of experience concerning work ability were identified in the narratives: confusion, coping with fluctuating symptoms, being 'in between' and being over the edge of exhaustion. Severe pain and fatigue symptoms, combined with a demanding life situation and ageing, seemed to lead to substantial decrease in work ability and functioning over the long term. In the narratives, vocational rehabilitation or adjustments to work tasks were rarely seen or were started too late to be effective. **Conclusions.** Exploring the life stories of women with fibromyalgia can reveal the perceived causes and consequences of fibromyalgia related to work ability or disability, which can be utilized in developing client-centred rehabilitation approaches and effective interventions to support work ability and avoid premature retirement in fibromyalgia patients. Copyright © 2009 John Wiley & Sons, Ltd.

Keywords
Fibromyalgia; functioning; narrative; rehabilitation; work ability

***Correspondence**
Merja Sallinen, Maamiehenkatu 10, 28500 Pori, Finland. Tel: +358 44 710 3768; Fax: 358 2 620 3440.
Email: merja.sallinen@samk.fi

Introduction

Fibromyalgia is a significant health problem in women of working age. The work ability of fibromyalgia patients is challenged by chronic widespread pain, allodynia, sleeping disorders and daytime tiredness. Although intensive, fluctuating pain and fatigue are the most prominent symptoms, patients can also have numerous other symptoms, such as depression, irritable bowel or concentration and memory problems (Clauw and Crofford, 2003; Dick et al., 2008). The prevalence of fibromyalgia is estimated to be 1–2% in the general population, but a prevalence as high as 8% has been reported in women aged 55–64 years (White et al., 1999a).

The aetiology and pathophysiology of fibromyalgia are not fully understood. In addition to central sensitivity syndromes, genetic disorders and psychosocial stress might be involved in the development of fibromyalgia. In the modern paradigm, fibromyalgia is seen as being at one end of continuum from no pain, through regional pain to widespread chronic pain (Ablin et al., 2008; Buskila, 2007; Yunus, 2007). Since the pathophysiology of fibromyalgia is unknown, no specific treatment is available. Various symptoms can, however, be alleviated with tailored medication, physical low-intensity exercises, cognitive-behavioural interventions or a combination of all of these (Mannerkorpi and Iversen, 2003; Sarzi-Puttini et al., 2008; Williams, 2003).

The natural history and long-term impact of fibromyalgia on everyday life are conflicting. The symptoms can be relatively stable and the quality of life can improve over time as patients learn to cope with the symptoms. However, the symptoms can be progressive over a long period, and spontaneous remission seldom occurs (Baumgartner et al., 2002; Mengshoel et al., 2001; Sim and Madden, 2008). In a review by Henriksson et al. (2005), 34–77% of patients were reported to be able to continue working in spite of fibromyalgia, especially when adjustments had been made to their work tasks and working hours. By contrast, 20–50% of patients were on a disability pension or other benefits. According to Liedberg et al. (2006), fibromyalgia caused substantial difficulties in the work performance even of young, recently diagnosed patients, whereas older patients seemed to cope better in a one-year follow-up.

The purpose of the present study was to explore the experiences of long-term fibromyalgia patients, in terms of their work ability and functioning, through their life stories. The specific issues addressed were how patients described their work ability and how changes in their work ability and functioning were connected to life events in their narratives. This study formed part of a multi-method follow-up study that was launched in 2007 at the Rheumatism Foundation in Finland to elucidate the long-term effects of fibromyalgia. The Ethical Committee of the Joint Authority for Päijät-Häme Social and Health Care approved the study design and methods.

Methods

Narrative research has its roots in the hermeneutic phenomenological tradition, focusing on the lived experiences of individuals, as well as the language that structures the experience (Bury, 1982; Polkinghorne, 1996). Polkinghorne (1996) also states that through ‘narrative knowing’ people come to understand the significance of past choices and events in relation to how things eventually turned out. As McAdams (1996) says, a life story ‘explains how Me of yesterday became Me of today and will become the anticipated Me of tomorrow’.

Patients’ narratives give voice to suffering in a way that lies outside the domain of biomedicine. Telling a life story helps the patient to explore the meanings of the experiences, reconstruct his or her identity and repair the mental and physical damage that the illness has inflicted on the body (Hydén, 1997). Moreover, exploring life stories may reveal important issues linking the illness experience, identity and cultural conventions of talking about the illness (Bury, 2001; Becker, 1999).

Participants

During 1999–2001, 169 patients participated in fibromyalgia rehabilitation courses at the Rheumatism Foundation Hospital. A letter containing information on the follow-up study and a consent form had been sent to all eligible patients in May 2007 (Figure 1). Age, professional background and location were used as selection criteria in purposive sampling, to reach informants in different life situations and hence to bring different aspects of functioning and work ability into discussion. Ultimately, 20 women, aged 34–65 years, participated in the interviews (Table 1).

Data collection

The first author (M.S.) conducted the narrative interviews following the ideas of Rosenthal (2003) and Wengraf (2001). Participants were reminded of the purpose of the study and reassured that they had the right to withdraw from the study at any point. They were also asked if they agreed to the interview being recorded and told that the recording device could be stopped later, if they found it disturbing.

Participants were first invited to tell their life story. A time limit of 30 minutes was suggested, but some participants took almost an hour to complete their account. In the second phase, participants were encouraged to elaborate their story through questions that emerged from the account. Typical questions were: ‘What happened after you…?’ or ‘Would you tell me more about this experience?’ The interview ended in

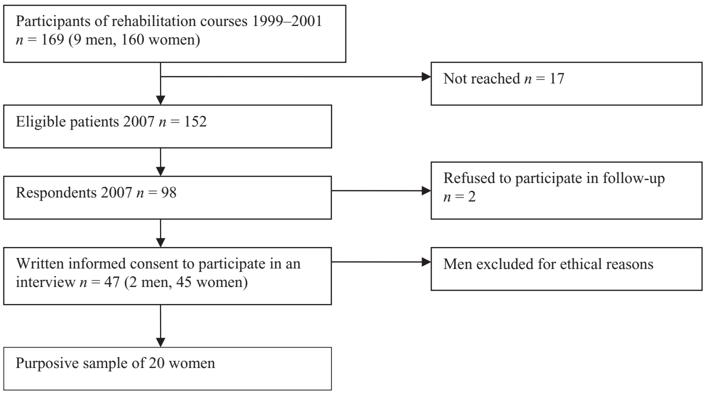


Figure 1 Sampling flow-chart

Table 1. Characteristics of the participants

Pseudonym	Age	Labour market status	Years with fibromyalgia-symptoms (years since diagnosis)	Occupation or type of work
Maria	53	Sick-listed	13 (12)	Assistant pharmacist
Aila	61	Disability pension	16 (15)	Cleaning
Raija	51	Sick-listed	25 (10)	Care of the elderly
Mirjam	52	Full-time work	20 (15)	Social work
Anna	52	Unemployed	15 (13)	Bank clerk
Terttu	63	Disability pension	28 (12)	Nanny
Laila	46	Full-time work	15 (10)	Nanny
Helena	45	Adjusted full-time work	15 (10)	Practical nurse
Taina	61	Disability pension	10 (9)	Pharmacist
Marita	51	Adjusted full-time work	25 (9)	Nanny
Lilli	34	Part-time work	14 (9)	Cleaning
Paula	65	Disability pension	20 (12)	Industrial work
Maija	57	Disability pension	18 (15)	Industrial work
Katri	58	Full-time work	10 (9)	Farming
Liisa	63	Pension due to age	20 (12)	Nurse
Anni	58	Disability pension	15 (10)	Nanny
Taru	49	Sick-listed, in re-education	15 (10)	Clerical work
Sara	49	Adjusted full-time work	25 (9)	Pre-school teacher
Iiris	59	Sick-listed	13 (10)	Pre-school teacher
Rita	60	Disablity pension	15 (10)	Practical nurse

free discussion. The interview session took two to four hours to complete.

Data analysis

The data were analysed in stepwise fashion, applying the ideas of Polkinghorne (1996) and Labov and Waletzky (2003). The first author had the main responsibility for the process, and the findings were peer reviewed by the second and third authors and then elaborated further. In the first stage of the analysis, the recorded material was listened through and the transcripts were read several times. The story was divided into identifiable episodes, which were then organized chronologically and a one-page core story of each interview was constructed. Finally, all the episodes and core stories were re-analysed to find repeated, recurrent or forceful expressions of work ability and functioning (Overcash, 2003).

Results

All but one of the 20 participants of the study could be considered to be of working age, but only six of them were still working full time. The women who were not in a paid work role at the time of the interviews were on permanent disability pension, on sick leave or unemployed. The narratives of the participants were powerful descriptions of life events, work and family life as they had experienced and interpreted them. They also included sensitive themes, such as mental health problems, family violence or death of a family member in their life stories and thus created intensive and evocative narratives.

In the analysis, four types of experience concerning work ability emerged: confusion, coping with fluctuating symptoms, being 'in between' and being over the edge. In some narratives, these episodes were consecutive, creating a linear storyline from work ability to disability. However, more commonly a dynamic movement back and forth between the four experiences was seen, often linked to the life situation in general.

Confusion

The experience labelled as 'confusion' was also expressed in the narratives as 'knowing but not knowing' or 'being lost'. The women had first paid little attention to waxing and waning symptoms, which were interpreted as temporary aches and pains that everyone has occasionally. Gradually, the symptoms became more intense and unpredictable, and began to disturb their working life. It was difficult to keep up a normal work performance because of tiredness and pain, described by participants as being somewhere and everywhere at the same time. The women knew that something was wrong but could not pinpoint what it was, as the extract from Anna's account illustrates:

> *'I was working long days, especially at the time of the bank mergers [in the beginning of the 1990s]... you always thought that it was the reason for being constantly tired and painful here and there... I could not sleep... there was this constant pain that you didn't know where it came from... it was travelling all the time; one day it was the left arm and the next day the right leg or back or neck...'* (Anna, 52)

The women had visited medical doctors several times, complaining of decreased work ability, pain and other symptoms, but to no effect. The comment 'there is nothing wrong with you' was repeated time after time. Often, healthcare staff and employers had directly said that the women had a mental health problem. The invisibility of fibromyalgia was experienced as an obstacle for being recognized as a real patient. Paula said:

> *'We had our own physician and a nurse, but they thought it was just... uhmm... you didn't really want to talk about it,'cause you would be seen as one of those who just think they are ill... they let you understand that it doesn't really exist... that is why it was difficult to seek help... they thought it was all in your head...'* (Paula, 65)

Coping with fluctuating symptoms

The women used phrases like 'learned to live with it' or 'I can manage' to express the experiences named here as 'coping with fluctuating symptoms'. In these experiences, the symptoms did not fade away but did not disturb the women's everyday life or work. Both formal and informal adjustments were made to support work ability and avoid spells of sick leave. Prioritizing work tasks and working at one's own pace were examples of informal adjustments. The women had also discussed their problems with colleagues and superiors in more formal situations. In some cases, it had led to adjustments concerning working hours or physically demanding tasks, which in turn helped them to continue at work. The effect of adjustments on work ability is described in the following extract:

> *'It was last spring when I stopped working night shifts for good... before that, it could be two to three night shifts in a row... then I spent the days taking painkillers to be able to work the next night... and we agreed to change it, because there were others who wanted to do nightshifts... it has been much easier for me ever since...'* (Helena, 45)

Participants compared their current work ability with that of their younger days, and identified their fibromyalgia symptoms as being as bad or even worse than they had been in the past. Other chronic health problems, such as arthrosis or cardiac symptoms, had developed with age, and these had also decreased their work ability. When a disability pension had finally been granted, it had been experienced as a relief, or, as one of the women put it, an amnesty. It gave them the opportunity to break down their activities into smaller tasks and to 'listen' to their bodies, both resulting in better coping. This is elucidated in the following extract:

> *'I also have other pains . . . degeneration of the joints and such . . . but now I of course cope fine, because I am just at home [on disability pension] . . . everything has changed for the better . . . I sleep better, with the proper medication . . . I have almost no symptoms now, only if I do something, I get sore . . . it is probably the whole thing that helped . . . the decrease in physical and mental burden, you know . . .'* (Aila, 61)

'Coping with fluctuating symptoms' gave participants a positive view of the future. They were able to continue in their social roles and activities, although some compromises were necessary. Coping was expressed as an acceptable goal of recovery, thus recognizing that full remission might not be possible.

In between

The experience that is labelled here as 'being in between' refers to the process of moving back and forth between full work ability and work disability. In the narratives, two types of 'in-between' experiences could be identified. Firstly, the women described situations where they were working in poor health, exceeding their capacity, which then led to sick leave due to overloading. The pain and sleeping problems caused a vicious circle of tiredness and muscular pain, which could no longer be relieved with sleep or painkillers. Their superiors did not always understand how much pain these women were experiencing, and behaved accordingly. Marita says:

> *'You were wondering at the gate of the workplace whether you should go to work or to see the doctor . . . the boss we had back then didn't understand at all . . . I had heavy medication then, like Tramal for the pains . . . and then she demanded that I return to work . . . two weeks was the maximum sick leave that she accepted . . .'* (Marita, 51)

Secondly, being 'in between' was explained at a more societal level. The women described how fibromyalgia combined with other symptoms had gradually forced them to take long-term sick leave, since adjustments to their work had not been made or had failed. Their previous work was no longer an option for maintaining the paid work role, yet access to permanent disability benefits was denied. This caused not only distress and anxiety, but also severe financial difficulties. Maija describes her situation:

> *'I was so angry; I had used the 300 days of temporary sickness benefits [maximum], and then I got a decision that said "you may be disabled but not in the sense that is meant in the legislation" . . . I cried my eyes out for weeks . . . what more did they want? . . . I was not unemployed, so I could not have any employment benefits either . . .'* (Maija, 57)

Maija's account also reflects the inability of the authorities to communicate with their clients in an understandable language and to offer advice on how to proceed after a negative decision has been made. Lack of early rehabilitation interventions was typical in the narratives and, for example, vocational rehabilitation was either not suggested or it had started too late to be effective. For some women, being 'in between' meant frustrating and depressing years of unemployment or part-time jobs, as suitable full-time work was not available.

Over the edge

The participants of the study discussed tiredness not only as a physiological lack of sleep, but also as a multidimensional, overwhelming exhaustion, where pain was intolerable, sleeping was seriously disturbed and their mood was depressed. Work was experienced as an extra burden, sapping their last drops of remaining energy. However, the women struggled on at work until they were physically and mentally too exhausted to continue. They described this experience as 'falling over the edge of exhaustion'.

The experience of being 'over the edge' was closely linked to difficult life situations in the women's accounts. Death of a close relative was often mentioned as a triggering event for exhaustion. In some cases, an accumulation of unwelcome events, such as domestic violence, divorce and loss of home, had eventually pushed the women over the edge. Iiris describes her situation:

> *'I was still going through the divorce process myself… and then at work, there were two kids that had experienced a violent divorce at home and I was supposed to take care of them… I told my boss, that I couldn't manage this… I don't have the resources now… and at the same time my ex wanted to move back in and when I did not agree he began to call me names and do all the other things… and then my son came down with a mental illness… I just ploughed through the autumn… I was so horribly tired and in pain and felt that I just couldn't take any more… then eventually one day I just could not go… [crying]… I sat with my winter coat on in the hall to go to work… but I just could not… my feet couldn't even carry me to the door…'* (Iiris, 59)

Many women referred to suicidal thoughts that they sometimes had, thus revealing moments of despair, even if the thoughts were quickly rejected. The fear that something bad might happen was concrete, as illustrated by the following quote from Anni's narrative:

> *In that sense, it was a relief that nothing dramatic happened… I was afraid that something might happen or I might do something… lose my grip and drop [a child]… if something had happened it would mean grief for evermore… I would never have forgiven myself had I hurt the children… or myself… you see, when you are totally exhausted, something* can *happen …*(Anni, 58)

The 'over the edge' experience undoubtedly represented the worst possible scenario in the narratives, and all participants had experienced it at some time. However, in the accounts, the time span varied individually, from days or weeks to several months. In some cases, return to work and recovery had been possible after the problematic life situation had been solved or after substantial reorganization of working hours and tasks had been carried out.

Discussion

Work ability, as experienced by women with a long history of fibromyalgia, could not be captured in a single definition, but in a spectrum of different ones. The 'confusion' experience reflected uncertainty in a new situation but was often resolved when more information was available. The experience of 'coping with fluctuating symptoms' was a success story; even when the symptoms continued, they caused no substantial problems in relation to work ability. The 'in-between' experience represented a more complicated situation, leaving the patient somewhere between work ability and disability. The fourth experience, 'being over the edge', was strongly associated with lack of control and overwhelming fatigue. These four experiences have similarities to the three themes of illness experiences that Sim and Madden (2008) found when reviewing qualitative studies on fibromyalgia: searching for diagnosis, legitimacy and coping. In the present study, however, participants' experiences of not coping in their working life were emphasized. The impact of ageing on fibromyalgia symptoms was frequently perceived as negative and the symptoms were experienced to be the same or even worse than before. Several chronic health problems had developed with age, which of course challenged work ability further. Many of the participants were already outside the labour market and their mean age was higher than that in previous studies, both of which might partially explain the impression of progressive deterioration in work ability in this study (Arnold et al., 2008; Liedberg et al., 2006; White et al., 1999b).

According to Undeland and Malterud (2007), receiving a diagnosis may be a turning point in the lives of people with unexplained symptoms. However, after the initial relief of having a diagnosis, uncertainty and stigmatization continue, since fibromyalgia does not seem to invoke recognition from either doctors or lay people. In a recent article, Yunus (2008) criticized the dualistic distinction of 'diseases' based on structural pathology and 'illnesses' based on experience. He pointed out that this distinction causes negative impacts on the care of patients, in terms of false attitudes and under-rated symptoms, which eventually increase the confusion of the patients. The present study supports this idea. Bearing in mind that most the participants of this study had received their diagnosis in the mid-1990s, when fibromyalgia was not well known, their experiences were strongly associated with a lack of credibility and legitimacy. Many women had suffered uncertainty for several years before the diagnosis was confirmed and appropriate treatment and rehabilitation was started.

The findings of this study confirm the results of Löfgren et al. (2006), indicating that rehabilitation measures are poorly adapted to supporting women with chronic pain conditions and that the lack of flexibility and support in the work place makes a return to work challenging, if not impossible. In the present results, early rehabilitation interventions were in many cases completely lacking, and the necessary adjustments to working tasks or hours had been started too late to be successful. Moreover, Nordenfeldt (2008) points out that work ability requires not only manual and intellectual competence for the specific task, but also sufficient physical, mental and social health and that the organizational work environment is acceptable or adjustable to the needs of the individual. The wish to be seen as a whole person with individual needs, instead of being fragmented by numerous diagnoses, was also forcefully expressed in the narratives of this study.

In the narratives describing the 'over the edge' experience, a return to work was perceived as unrealistic, not only because of the physical, psychological, emotional and social limitations of the women, but also because of the unbearable life situation. This finding is in accordance with the results of Henriksson et al. (2005), who remind us that not only the prominent symptoms, but also the whole-life situation should be considered when determining whether a person can continue to work.

Methodological considerations

According to Malterud (2001), the rigour of qualitative research can be evaluated through reflexivity and transparency, as well as transferability of the research process. The data from this study were collected and transcribed by one researcher. The fact that the majority of the participants were middle-aged women might have had a positive effect on the conduct and content of the interview sessions. The fact that the women voluntarily included sensitive and intimate life events in their stories suggested that the interviewer was perceived as reliable and easy to approach. This enabled rich and evocative narratives to be produced.

The study was open to both men and women, but only two men volunteered for the interviews. It was possible, but unlikely, that they would have been able to be identified, owing to the small number of men in the original rehabilitation groups, so we therefore decided to include only women in this study. Although fibromyalgia and chronic widespread pain are more common in the female population, men should be included in future studies, to assess the impact of fibromyalgia on their work ability, as their occupational demands might be very different from those of women.

It is possible that the narrated life stories were biased because of memory distortion or emotional loading. This was counteracted by asking questions concerning life events later in the interview, and thus deepening the meanings and connotations of these events in the participant's life. Although the findings of a narrative study should not be generalized for population groups at large, it is possible to discuss the transferability of the results to another group of patients (Malterud, 2001). It is likely that numerous middle-aged women with fibromyalgia could tell similar stories to those included in this study. The inclusion of authentic extracts was intended to give the reader the possibility of assessing the relevance of the findings in relation to other situations and settings and thus to reflect on the credibility and trustworthiness of the findings.

This narrative analysis concerned a relatively small number of cases, and further research is needed to establish the long-term effects of fibromyalgia on functioning and work ability. It is possible that women with more severe problems in functioning were more eager to participate in the interviews than those who were still working. Most of the participants in this study were already out of the labour market and only a few were working full time. The question of whether this reflects the development of work disability in fibromyalgia on a more general level remains to be elucidated.

Conclusions

The findings of this study show inter- and intraindividual variation in functioning and work ability in women with a long history of fibromyalgia. Severe pain and fatigue symptoms, combined with a demanding life situation and ageing, seem to lead to a substantial decrease in work ability and functioning in the long term. Recognizing the experiences of being 'in between' and 'over the edge' is essential in occupational health care, in the work place and in rehabilitation settings. These findings indicate that fibromyalgia patients with complicated lives are at high risk of dropping out of the labour market permanently and need innovative and well-timed rehabilitation interventions to support their empowerment, overall functioning and work ability.

Acknowledgements

The research project was supported by Rheumatrism Foundation Hospital, Heinola, Finland through research grants for Ms Sallinen and PhD Kukkurainen.

REFERENCES

Ablin J, Neumann L, Buskila D (2008). Pathogenesis of fibromyalgia – A review. Joint Bone Spine: Revue du Rhumatisme 75: 273–9.

Arnold LM, Crofford LJ, Mease PJ, Burgess SM, Palmer SC, Abetz L, Martin SA (2008). Patient perspectives on the impact of fibromyalgia. Patient Education and Counseling 73: 114–20.

Baumgartner E, Finckh A, Cedraschi C, Vischer TL (2002). A six-year prospective study of a cohort of patients with fibromyalgia. Annals of the Rheumatic Diseases 61: 644–5.

Becker B (1999). Narratives of pain in later life and conventions of storytelling. Journal of Aging Studies 13: 73–87.

Bury M (1982). Chronic illness as a biographical disruption. Sociology of Health and Illness 4: 167–82.

Bury M (2001). Illness narratives: Fact or fiction. Sociology of Health and Illness 23: 263–85.

Buskila D (2007). Genetics in chronic pain states. Best Practice & Research Clinical Rheumatology 21: 535–47.

Clauw DJ, Crofford LJ (2003). Chronic widespread pain and fibromyalgia: What we know and what we need to know. Best Practise & Research Clinical Rheumatology 17: 685–701.

Dick BD, Verrier MJ, Harker KT, Rashiq S (2008). Disruption of cognitive function in fibromyalgia syndrome. Pain 139: 610–16.

Henriksson CM, Liedberg GM, Gerdle B (2005). Women with fibromyalgia: Work and rehabilitation. Disability and Rehabilitation 27: 685–95.

Hydén L-C (1997). Illness and narrative. Sociology of Health and Illness 19: 48–69.

Labov W, Waletzky J (2003). Narrative analysis: Oral versions of personal experiences [reprint from 1967]. In Bratt Paulston C, Tucker GR (Eds). Sociolinguistics: The Essential Readings. Oxford: Blackwell.

Liedberg GM, Burckhardt CS, Henriksson CM (2006). Young women with fibromyalgia in the United States and Sweden: Perceived difficulties during the first year after diagnosis. Disability and Rehabilitation 28: 1177–84.

Löfgren M, Ekholm J, Öhman A (2006). 'A constant struggle': Successful strategies of women in work despite fibromyalgia. Disability and Rehabilitation 28: 447–55.

McAdams DP (1996). Narrating the self in adulthood. In Birren JE et al. (Eds). Aging and Biography; Explorations in Adult Development. New York, NY: Springer: 131–49.

Malterud K (2001). Qualitative research: Standards, challenges and guidelines. Lancet 358: 483–8.

Mannerkorpi K, Iversen MD (2003). Physical exercise in fibromyalgia and related syndromes. Best Practice & Research Clinical Rheumatology 17: 629–47.

Mengshoel AM, Haugen M (2001). Health status in fibromyalgia – A follow-up study. Journal of Rheumatology 28: 2085–9.

Nordenfeldt L (2008).The concept of work ability. Brussels: PIE Peter Lang.

Overcash J (2003). Narrative research: A review of methodology and relevance to clinical practice. Critical Reviews in Oncology/Hematology 48: 179–84.

Polkinghorne DE (1996). Narrative knowing and the study of lives. In Birren JE et al. (Eds). Aging and Biography: Explorations in Adult Development. New York, NY: Springer: 77–99.

Rosenthal G (2003). The healing effects of storytelling: On the conditions of curative storytelling in the context of research and counselling. Qualitative Inquiry 9: 915–33.

Sarzi-Puttini P, Buskila D, Carrabba M, Doria A, Atzeni F (2008). Treatment strategy in fibromyalgia syndrome: Where are we now? Seminars in Arthritis & Rheumatism 37: 353–65.

Sim J, Madden S (2008). Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. Social Science and Medicine 67: 57–67.

Undeland M, Malterud K (2007). The fibromyalgia diagnosis – Hardly helpful for the patients? A qualitative focus group study. Scandinavian Journal of Primary Health Care 25: 250–5.

Wengraf T (2001). Qualitative research interviewing: Biographic narrative and semi-structured methods. London: Sage.

White KP, Speechley M, Harth M, Ostbye T (1999a). The London Fibromyalgia Epidemiology Study: The prevalence of fibromyalgia syndrome in London, Ontario. Journal of Rheumatology 26: 1570–6.

White KP, Speechley M, Harth M, Ostbye T (1999b). Comparing self-reported function and work disability in 100 community cases of fibromyalgia syndrome versus controls in London, Ontario. Arthritis & Rheumatism 42: 76–83.

Williams DA (2003). Psychological and behavioural therapies in fibromyalgia and related syndromes.

Best Practice & Research Clinical Rheumatology 17: 649–65.

Yunus MB (2007). Fibromyalgia and overlapping disorders: The unifying concept of central sensitivity syndromes. Seminars in Arthritis & Rheumatism 36: 339–56.

Yunus MB (2008). Central sensitivity syndromes: A new paradigm and group nosology for fibromyalgia and overlapping conditions, and the related issue of disease versus illness. Seminars in Arthritis & Rheumatism 37: 339–52.

II

"I'M TIRED OF BEING TIRED" – FATIGUE AS EXPERIENCED BY WOMEN WITH FIBROMYALGIA

by

Sallinen M, Kukkurainen ML, Peltokallio L & Mikkelsson M, 2011

Advances in Physiotherapy 13, 11-17

Advances in Physiotherapy, 2011; 13: 11–17

ORIGINAL ARTICLE

"I'm tired of being tired" – Fatigue as experienced by women with fibromyalgia

MERJA SALLINEN[1], MARJA LEENA KUKKURAINEN[2], LIISA PELTOKALLIO[3] & MARJA MIKKELSSON[4]

[1]*Satakunta University of Applied Sciences, Pori, Finland,* [2]*Rheumatism Foundation Hospital, Heinola, Finland,* [3]*Department of Health Sciences, University of Jyväskylä, Finland,* [4]*Päijät-Häme Central Hospital, Lahti, Finland*

Abstract
The aim of the study was to explore how fatigue was experienced and explained in life stories of women with a long history of fibromyalgia to gain a deeper understanding of fatigue as a phenomenon. The data was drawn from the narrative interviews of 20 purposively chosen women with fibromyalgia. In the analysis, the ideas of episodic reading and paradigmatic analysis of narratives were used to find recurrent and repeated experiences of fatigue from the data. Five main themes emerged from the data: sleepless nights, physical weakness, loss of mental energy, social withdrawal and overwhelming exhaustion. The narratives indicated that in fibromyalgia, fatigue is a transient, extreme and intensive experience, which causes major disability and distress and which has consequences on every aspect of life. A deeper understanding of the multi-dimensionality of fatigue may help physiotherapists and other health professionals to increase the relevance and effectiveness of the interventions aimed at fibromyalgia patients who complain of fatigue.

Key words: *Pain, qualitative research, rehabilitation*

Introduction

Fatigue as a chronic symptom is a well-known manifestation of a number of chronic diseases like cancer, multiple sclerosis and stroke (1–3), but it is also prevalent in pain-related disorders, such as rheumatoid arthritis (4) and chronic widespread pain (5). According to Sonnenschein et al. (6), fatigue can be defined as a subjective feeling of low vitality that disrupts daily functioning and that ranges from tiredness to severe exhaustion. They defined tiredness as a common short-lived physical experience, which in most cases disappears with rest, whereas exhaustion is labelled with depressive symptoms, work-related disability and physiological alterations of the endocrine functions.

In fibromyalgia, fatigue is one of the core symptoms, in addition to chronic widespread pain, tenderness and allodynia (7,8). Theadom et al. (9) noticed that up to 99% of fibromyalgia patients report poor sleep quality, which significantly predicts increased pain and fatigue. The overall level of daily fatigue is rated higher in fibromyalgia, and the patients show greater day-to-day variance in fatigue and vitality compared with patients with rheumatoid arthritis or osteoarthritis (10). Crooks (11) in turn noticed that sleeping problems and fatigue force fibromyalgia patients to change their daily routines and to pace their activities to manage the symptoms, thus decreasing their ability to work and to participate in hobbies and recreational activities.

Although neither a single cause nor cure for fibromyalgia has yet been found, there is growing evidence that physiotherapy interventions such as aerobic exercise, strength training and balance and coordination exercises are beneficial in the treatment of fibromyalgia (12,13). However, research suggests that dropout rate may be high and exercise adherence may be low among this patient group (14), and this may in part be a result of perceived fatigue. In this qualitative study, we explored the narrated life stories of women with a long

---

Correspondence: Merja Sallinen, Satakunta University of Applied Sciences, Maamiehenkatu 10, 28500 Pori, Finland. Tel: 358-44-7103768. E-mail: merja.sallinen@samk.fi

(Received 16 September 2010; accepted 7 December 2010)

ISSN 1403-8196 print/ISSN 1651-1948 online © 2011 Informa Healthcare
DOI: 10.3109/14038196.2010.546880

history of fibromyalgia in order to gain a deeper understanding of the meanings of fatigue in their everyday life and functioning. The purpose was to illuminate how fatigue was experienced and explained in the narratives, and what was the perceived impact of fatigue on functioning in a long-term perspective.

Methods and participants

Narrative approach

According to Bruner (15), we tend to organize our experiences in a form of a narrative to make sense of life and to construct our identity. Narrativity assumes active agency of the narrator in order to re-interpret one's life events and to reconstruct a coherent life story. Moreover, it has the potential of showing how participants link events and experiences together and what the significance is attributed to the experiences (16). However, as Atkinson (17) points out, a personal narrative is not meant to be read as an exact record of events; rather than that, it reveals a certain unique point of view. Narratives can be seen as a co-constructed result of interaction between the narrator and the listener, in which the intentions, beliefs, desires, fears and values of the narrator are explicated in the form of a story (18,19). Furthermore, dialogue with the interviewer may open new perspectives and prompt the individual to focus on previously unnoticed experiences (20). In this study, narrativity was used both as a philosophical approach and as a method of collecting data, which gives a voice to the participants' experiences and interpretations.

Participants

The present narrative study forms part of a multi-method follow-up study of patients (n = 169) who participated in fibromyalgia rehabilitation courses at Rheumatism Foundation Hospital during 1999–2001 (the Hospital was closed down in April 2010). In addition to specialized hospital care and orthopaedics, the Rheumatism Foundation Hospital provided rehabilitation courses for patients with various rheumatic conditions, including fibromyalgia. The rehabilitation courses were funded by the Social Insurance Institution (SII), and the regional offices of SII selected the patients based on application and doctor's referral. Each fibromyalgia-specific rehabilitation course of 10–12 patients was completed in 17–20 days, divided into two or three intensive inpatient periods within 6 months. The daily programme comprised lectures, group discussions, physiotherapy group exercises, relaxation exercises and some individual treatments. However, the emphasis was on education and counselling instead of treatment of symptoms as such.

After the local ethics committee approved the study design and methods of the follow-up study, all eligible participants (n = 152) were approached with an information letter, a questionnaire on personal information and a consent form. Ninety-six respondents gave their informed consent to the follow-up study and 47 volunteered for the interview study. Age, professional background and location were used as criteria in purposive sampling aiming at maximal variation. The sampling process is presented in detail in the flow chart (Figure 1).

The sample consisted of 20 middle-aged women from both rural and urban areas from different parts of the country. The mean age of the participants was 54 years, ranging from 34 to 65 years. The duration of fibromyalgia symptoms was on average 17 years (range 10–30 years), but in most cases diagnosis had not been confirmed until several years later; the time since diagnosis was on average 11 years (range 10–15 years). The professional background of the participants

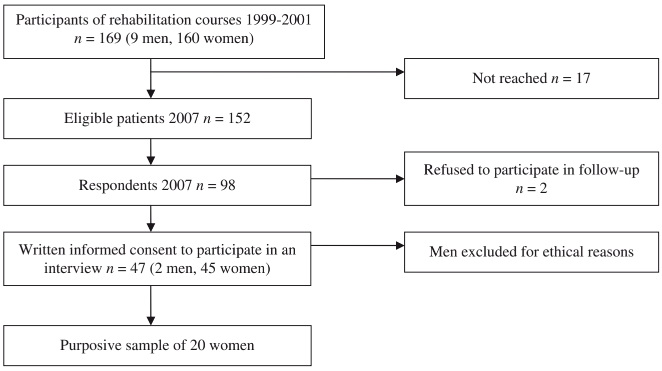


Figure 1. Sampling flow-chart.

represented professions that can be considered typical among Finnish women, such as nursing, teaching, office or industrial work. However, at the time of the interviews only six of the participants were full-time workers, seven were on a permanent disability pension, three were part-time workers or unemployed, another three were sick-listed and one participant had retired because of old age.

Data collection and analysis

Data were collected by a narrative interview method inspired by Rosenthal (21) and Wengraf (22). The first author conducted all the interviews in August–October 2007 at the time and place chosen by the participants, in most cases in their homes. At the beginning of the interview, the participants were reminded of the purpose and context of the study and of their right to withdraw at any point. The participants were first invited to tell their life story in their own words, including events of their own choice. Then the account was reflected upon and enriched through questions on the themes emerging from the account. The interview was closed with a general discussion, which gave the participant a possibility to discuss her own situation further and ask about e.g. current advances in the treatment of fibromyalgia or to comment on the study in question. It also gave the interviewer a possibility to observe the participants for a while and make sure that they were at ease after sharing their life stories, which were often emotionally loaded. The whole interview session thus took 2–4 h.

The data analysis was built on methods described by Polkinghorne (23) and Riessman (24). The recorded material was listened to and the verbatim transcripts were read through several times to capture the "whole" of each interview. Each life story consisted of a series of episodes describing important life events and interpreting causes and consequences of the events. In the second stage of the analysis, these episodes – the stories within the story – were identified (25). The identified episodes were organized chronologically to reconstruct a core story of each narrative. In the final stage, the episodes and the core stories were re-analysed across the data of 20 interviews to find repeated, recurrent and forceful experiences of fatigue.

Results

Fatigue was the most common topic of discussion in the data, and many women described it as the most problematic symptom of fibromyalgia, even when compared with chronic pain. The intensity of fatigue varied on a day-to-day basis and fatigue was therefore perceived as a severe and unpredictable problem. In the narratives, fatigue was not only linked to pain or sleeping problems, but to demanding life events in general. In the following, the results of the analysis are represented under five themes that emerged from the data: sleepless nights, physical weakness, loss of mental energy, social withdrawal and overwhelming exhaustion.

In the extracts, pseudonyms are used and some identifying details have been deleted or changed to protect the integrity and anonymity of the participants.

Sleepless nights

Sleeping problems were familiar to all participants. In the narratives, the severity of sleeping problems varied from occasional problems to a constant lack of sleep. Fatigue was perceived both as a cause and a consequence of chronic pain, and many women found it difficult to say which had started first. In many narratives, sleeping problems were connected to workload, especially if the working hours were irregular, as in nursing or industrial work. The following excerpt highlights this issue:

> [After a night shift] I slept maybe an hour or hour and a half a day … you know how it is when you don't sleep practically at all for weeks and months … In fact, I was practically sleepless for years … I don't know how I managed to drive the car with all that medication I had back then … and the pain … it was like some spike or thread was pulled through every joint of the body… once I woke up in the middle of the nightmare where I was tortured by the Nazis … (Liisa, 63)

Over the years, the participants had developed various methods to increase the amount and quality of sleep. Some of them had started for example winter swimming or exercising in the evenings to help them fall asleep. Using sleeping pills was usually not seen as an option because of side-effects, such as "foggy mornings". Medication was described as the last option, used only if nothing else seemed to help. The participants who were not in paid work because of disability or sickness benefits pointed out that pacing of activities was now possible. On the one hand, knowing that you do not have to concentrate on working tasks reduced the stress caused by sleeplessness. On the other hand, disability pension or sick listings were perceived as giving in to fatigue.

Physical weakness

The participants often described fatigue as physical weakness, especially in connection with early pain symptoms. Muscular weakness or loss of strength developed gradually and was at first explained to be caused by temporary pains and aches or physical overloading. In many narratives, the experience of physical weakness had increased over the years and caused substantial difficulties in leisure time activities and household tasks. The following extract elucidates how Taina anticipated the consequences of physical loading in her daily activities:

> I have to decide, you know … for example if there is a heavy cleaning job to be done, I have to decide that *tomorrow* is the day … then I do it and suffer from it later on … because it takes time to recover … (Taina, 61)

The experience of physical weakness was strongly linked with work ability and disability. The participants told how they constantly struggled to complete their work tasks, and how worn out they were after a working day. The following extract describes Arja's situation just before a long sick leave:

> Well, I will remember that Saturday forever … one of us used to work on Saturdays, you see … it was always a busy day anyway … and we have residents' accommodation at one end of the building and our locker room is at the other end, and the corridor in between is maybe a hundred metres long … I could barely cover that distance at the end of that day … I was so tired once and for all … so tired … (Arja, 61)

After the rehabilitation course, many participants had taken up light exercising to improve their physical fitness. However, they confessed that over time, their motivation had decreased and exercising had become more irregular. They had noticed that recovery of the muscles took longer and muscular pain after physical activity was worse than earlier. This easily led to giving up physical loading, such as exercising and heavy household work, although many participants had recognized the risks of inactivity. It was also perceived as challenging to find the energy for exercising when the pain and fatigue were intense.

Social withdrawal

In the narratives, social relations were largely influenced by fatigue. Many of the participants worked in fields where social interaction with colleagues and clients was expected. However, sometimes even talking or listening to others was found to be too demanding because of fatigue. The following excerpt sheds light on this perspective:

> I was quiet and withdrew from the work team … it was a huge effort for me to chat … I preferred to visit places [in elderly care] where I knew that I would not need to talk … (Ritva, 51)

The demands of social life were sometimes seen to be beyond one's capacity, and some participants had therefore decided not to invite people over or to visit friends. In some cases, relationship with husband or other family members was also disrupted because of fatigue. The women felt that they were no longer able to be the wife or mother they used to be because of the constant fatigue and pain. Not only had the responsibilities for domestic work, but also emotional and intimate life changed. Some participants used social withdrawal as a method to protect their family members instead of burdening them. Pirjo explains this as follows:

> As the poet says: "into the peace of the gorge /I creep like a beast/ to die … " … You see, it is easy to shut the door from the rest of the world … it is not only that I want to wallow in self-pity … but more like … I don't want to be a burden to anyone … you see … I can be a real bitch sometimes … especially when I am tired and in pain … (Pirjo, 60)

Loss of mental energy

The experience named here as "loss of mental energy" was described in the narratives as a process labelled with loss of initiative and joy or with depressive thoughts and low self-esteem. The participants pointed out the inner change they had noticed. The former energetic, happy and hardworking woman had turned into a constantly tired, sad and depressed woman with difficulties in finding the energy to get dressed, not to mention managing a working day. The following excerpt highlights this kind of transition:

> I got a trip to City X as a gift … I spent 10 days there and all the time I felt that I was in the wrong place … I did not enjoy it at all … what has happened to me that I cannot enjoy things like this anymore? … I don't prepare food for days … and I don't find the energy to clean the house … I used to be a hard-working woman, you see … and active in society, too … but now … all that has changed … (Ritva, 51)

Many participants shared openly their experiences of mental health problems like depression, which was often explicated as a form of excessive fatigue. Loss of mental energy was perceived as an unwanted, neglected and rejected form of fatigue, which was seldom discussed with health professionals. This was because of the experience that such discussion would only lead to more medication instead of other types of help or support. Moreover, they explained that the loss of mental energy was frequently belittled with comments such as "if you are tired, you should go to bed earlier" or "pull yourself together". The participants were annoyed and frustrated by these comments, especially when hearing those from health professionals, who might be expected to be aware of the participants' situation.

Overwhelming exhaustion

The experience named here as "overwhelming exhaustion" was also expressed as "fibro-days" or "collapse". Many participants explained how the situation deteriorated when disturbed sleep or excessive workload was combined with a complex life situation or cumulating daily hassles. The participants continued to work when in poor condition, but eventually sick leave was inevitable because of exhaustion. The whole narrative of "Irene" represented the overwhelming exhaustion that she was suffering from at the time of the interview. Her narrative was chaotic, extremely emotional and she burst into tears several times during the interview. However, she was determined to tell her whole life story, which included tragic events in her family, difficulties at work and financial problems. As a result of her demanding life situation, her pains and aches and fatigue had increased dramatically and she had been practically bed-ridden for weeks. In the following quotation, she summarizes the situation:

> At this moment I think … with all the children living on their own … that my situation is … that nobody needs me anymore … there isn't anything [crying] … I have no strength to go on … I don't expect anything … if there is a future … if only I could recover … but now I feel that I have no resources now … I am too exhausted … I'm so tired of being tired, you see … (Irene, 59)

In most cases, the sick listing for exhaustion could last for weeks or months, and the participants were convinced that the development of the situation could and should have been intervened with earlier. They found it conflicting that physicians often only focused on blood tests or X-rays instead of discussing the functional limitations or the entire life situation when evaluating work ability. As a result nothing "inflammatory" was found, no interventions were started, and over time, the exhaustion evolved into a comprehensive and crushing fatigue experience, which not only caused work disability, but also severe limitations in daily functioning at home.

Discussion

The purpose of this study was to shed light on the experiences of fatigue in fibromyalgia. We will first address some limitations of the study before discussing the substantial findings.

In this study, purposive sampling was used to reach a rich variety of experiences. The main limitation regarding the sampling is that we were not able to recruit men to our study. Only two men volunteered for the interviews, but they were excluded for ethical reasons. It was possible, yet unlikely, that they could have been identified because of the small number of men in the original rehabilitation groups. However, our sample of 20 middle-aged women with fibromyalgia can be considered representative of the patient group in question; the majority of fibromyalgia patients are women in midlife (8,26). Secondly, the sample size of 20 participants is relatively small, and it is possible that in a bigger sample some other experiences might emerge than those described here. In narrative study, the aim is to reach a thorough analysis and deep knowledge on the study material and on what in the data is relevant to the research question (27). In this study, the amount of data served our purposes more than sufficiently, enabling versatile and rigorous review and analysis of the data. We believe that fatigue experiences similar to those described here could also be elicited from other patients with fibromyalgia. The results are thus transferable to other situations and settings with fibromyalgia patients, although they cannot be generalized to the population at large (17,27). Finally, in this study every third participant was on permanent disability benefit, which is a substantially higher rate than in earlier qualitative studies (28–30). This difference could be partially explained by the older age and long illness history of the participants in the present study. It is also possible that people who were not in paid work were more eager to participate in an interview study compared with those in full-time work.

The most striking finding of the present study was the sheer diversity and intensity of the experiences of fatigue. The evocativeness of the narratives can be seen as a strength of the study. Fatigue was perceived as an unpredictable symptom that decreased substantially work ability and functioning in everyday activities. As some of the participants explicated, one can learn to tolerate the pain, but combined with fatigue it changes one's whole life into suffering. In the narratives, fatigue was seen as the most disturbing problem, whereas pain was first and foremost referred to as an early sign of fibromyalgia or as a "lifelong companion one has to deal with". In the present study, fatigue was often discussed in the context of working life and work-related disability. Work ability was not only threatened by daytime tiredness after a sleepless night or decrease in physical endurance, but also by decrease in vitality and by challenges in social interaction, which were perceived as results of constant, uncontrolled fatigue. These findings accord with, and add more detailed knowledge to, earlier findings by Henriksson et al. (31), who pointed out that perceived fatigue predicts physical impairment and work disability, and could thus be an even more dominant disabler than chronic pain in working-age patients with fibromyalgia.

In our data, psychosocial elements of fatigue were emphasized, and in some of the narratives, the experiences of fatigue and depression seemed to overlap. This was especially apparent in the narratives describing overwhelming fatigue where depressive symptoms, hopelessness and despair formed a substantial part of the experience. In modern society, mental health problems carry a heavy negative stigma, and therefore it can be more socially acceptable to discuss tiredness and fatigue than anxiety and depression. It is also possible that in fibromyalgia, depression, pain and fatigue are so tightly interwoven that they can no longer be perceived as separate experiences but as one entity. Moreover, our results suggest that depression among fibromyalgia patients may be insufficiently recognized and treated, and the severity of the symptoms may be underrated or belittled by professionals.

Rijk et al. (32) pointed out that finding and engaging in pleasurable activities may have a positive effect on a wide variety of fatigue sensations, whereas reduction of overload can only have impact on physical fatigue. In physiotherapy, the physical elements of fatigue, such as muscular fatigue and sleeping problems, are often emphasized, whereas psychosocial elements and the multi-dimensional nature of fatigue are rarely appreciated. In physiotherapy, we have tools to help these patients by combining exercise therapy with creative movement therapies, dance or various outdoor activities, thus increasing the elements of joy and pleasure in their daily life. It may also be necessary to apply therapy interventions according to the type of fatigue to gain better results, e.g. patients who suffer from social fatigue may not benefit from group exercises or educational groups but from a more individual approach. Furthermore, as our results show, we must first understand what the patients with fibromyalgia actually mean when they talk about fatigue.

Conclusions

The narratives of the present study indicate that in fibromyalgia, fatigue is a transient, extreme and intensive experience, which causes major disability and distress, and which has consequences on every aspect of life. The long-term impacts of fatigue can be expressed in terms of gradual deterioration of work ability and physical functioning, decrease in mental resources as well as decrease in participation in social activities. Moreover, fatigue may bias the identity and self-perception of patients with fibromyalgia, which may in turn have a detrimental impact on their treatment compliance and exercise adherence.

Practical implications

Fatigue should and could be recognized early to prevent severe fatigue-related problems and deterioration of overall functioning. A deeper understanding of fatigue as a multi-dimensional phenomenon may help physiotherapists and other health professionals to address problems that are hidden behind the phrase "I'm too tired" and may thus help them plan and implement more relevant and effective interventions for fibromyalgia patients.

Acknowledgements

We want to thank the participants of the study for sharing their stories with us. We also thank Anu Vuolteenaho, MSc for language revisions. The study was funded by research grants from Rheumatism Foundation Hospital and Finnish Cultural Foundation's Regional Fund in Satakunta.

Declaration of interest: The authors declare no conflict of interest in the writing of this paper.

References

1. Wu H-S, McSweeney M. Cancer-related fatigue: "It's so much more than just being tired". Eur J Onc Nurs. 2007; 11:117–25.
2. Vucic S, Burke D, Kiernan M. Fatigue in multiple sclerosis: Mechanism and management. Clin Neurophys. 2010;121: 809–17.
3. Schepers V, Visser-Meily A, Ketelaar M, Lindeman E. Post-stroke fatigue: Course and its relation to personal and stroke-related factors. Arch Phys Med Rehabil. 2006;87:184–8.
4. Hewlett S, Cockshott Z, Byron M, Kitchen K, Tipler S, Pope D, et al. Patients' perceptions of fatigue in rheumatoid arthritis: Overwhelming, uncontrollable, ignored. Arthritis Rheum. 2005;53:697–702.
5. Cieza A, Stucki G, Weigl M, Kullman L, Stoll T, Kamen L, et al. ICF core sets for chronic widespread pain. J Rehab Med suppl.. 2004;44:63–8.
6. Sonnenshcein M, Mommersteeg P, Houtveen J, Sorbi M, Schaufeli W, van Doornen L. Exhaustion and endocrine function in clinical burnout. An in-depth study using the experience sampling method. Biol Psych. 2007;745:176–84
7. Arnold LM, Crofford LJ, Mease PJ, Burgess SM, Palmer SC, Abetz L, et al. Patient perspectives on the impact of fibromyalgia. Patient Educ Couns. 2008;73:114–20.
8. Wolfe F, Clauw DJ, Fitzcharles MA, Goldenberg DL, Katz RS, Mease P, et al. The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom severity. Arthritis Care Res. 2010;62: 600–10.

9. Theadom A, Cropley M, Humphrey K-L. Exploring the role of sleep and coping in quality of life in fibromyalgia. J Psychosom Res. 2007;62:145–51.
10. Zautra AJ, Fasman R, Parish BP, Davis MC. Daily fatigue in women with osteoarthritis, rheumatoid arthritis and fibromyalgia. Pain. 2007;128:128–35.
11. Crooks V. Exploring the daily geographies and life worlds of women living with fibromyalgia syndrome: A mixed method approach. Soc Sci Med. 2007;64:577– 88.
12. Häuser W, Thieme K, Turk DC. Guidelines on the management of fibromyalgia syndrome – A systematic review. Eur J Pain. 2010;14:5–10.
13. Carville S, Arendt-Nielsen S, Bliddal H, Boltman F, Branco JC, Buskila D, et al. EULAR recommendations for the management of fibromyalgia syndrome. Ann Rheum Dis. 2008;67:536–41.
14. Mannerkorpi K, Iversen MD. Physical exercise in fibromyalgia and related syndromes. Best Pract Res Clin Rheum. 2003:17:629–47.
15. Bruner J. Life as narrative. Soc Res. 2004;71:691–710.
16. Steihaug S, Malterud K. Stories about bodies: A narrative study on self- understanding and chronic pain. Scan J Prim Health Care. 2008;26:188–92.
17. Atkinson R. The life story interview. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: Context & method. Thousand Oaks, CA: Sage; 2001. p 121–38.
18. Bury M. Illness narratives: Fact or fiction? Soc Health Illness. 2001;23:263–85.
19. Hydén LC. Illness and narrative. Soc Health Illness. 1997;129:48–69.
20. Hänninen V. A model of narrative circulation. Narr Inq. 2004;14:69–85.
21. Rosenthal G. The healing effects of storytelling: On the conditions of curative storytelling in the context of research and counselling. Qual Inq. 2003;9:915–33.
22. Wengraf T. Qualitative research interviewing: Biographic narrative and semi- structured methods. London: Sage; 2001. p 118–45.
23. Polkinghorne DE. Narrative knowing and the study of lives. In: Birren JE, Kenyon GM, Ruth JE, Schroots JJ, Svensson T, editors. Aging and biography: Explorations in adult development. New York: Springer; 1996. p 77–99.
24. Riessman C. Analysis of personal narratives. In: Gubrium JF, Holstein JA, editors. Handbook of interview research: Context & method. Thousand Oaks, CA: Sage; 2001. p 595–708.
25. Labov W, Waletzky J. Narrative analysis: Oral versions of personal experiences [reprint from 1967]. In: Bratt Paulston C, Tucker GR, editors. Sociolinguistics: The essential readings. Oxford: Blackwell; 2003. p 74–104.
26. Buskila D. Fibromyalgia: The diagnosis and pharmacologic treatment. Eur J Pain Suppl. 2009;3:111–15.
27. Malterud K. Qualitative research: Standards, challenges and guidelines. Lancet. 2001;358:483–8.
28. Söderberg S, Lundman B, Norberg A. The meaning of fatigue and tiredness as narrated by women with fibromyalgia and healthy women. J Clin Nurs. 2002;11:247–55.
29. Liedberg GM, Burckhardt CS, Henriksson, CM. Young women with fibromyalgia in the United States and Sweden: Perceived difficulties during the first year after diagnosis. Disabil Rehabil. 2006;28:1177–84.
30. Löfgren M, Ekholm J, Öhman A. “A constant struggle”: Successful strategies of women in work despite fibromyalgia. Disabil Rehabil. 2006;28:447–55.
31. Henriksson CM, Liedberg GM, Gerdle B. Women with fibromyalgia: Work and rehabilitation. Disabil Rehabil. 2005; 27:685–95.
32. Rijk A, Schreurs K, Benzing J. What is behind “I’m so tired”? Fatigue experiences and their relations to the quality and quantity on external stimulation. J Psychosom Res. 1999; 47:509–23.

III

FINALLY HEARD, BELIEVED AND ACCEPTED – PEER SUPPORT IN THE NARRATIVES OF WOMEN WITH FIBROMYALGIA

by

Sallinen M, Kukkurainen ML & Peltokallio , 2011

Patient Education and Counseling 85; e126 - e130.

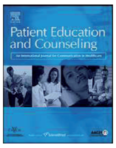
Reproduced with kind permission by Elsevier

Patient Education and Counseling 85 (2011) e126–e130

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Patient Perception, Preference and Participation

Finally heard, believed and accepted – Peer support in the narratives of women with fibromyalgia

Merja Sallinen [a,*], Marja Leena Kukkurainen [b], Liisa Peltokallio [c]

[a] *Satakunta University of Applied Sciences, 28500 Pori, Finland*
[b] *Rheumatism Foundation Hospital in Heinola, 18100 Heinola, Finland*
[c] *University of Jyväskylä, Faculty of Sports and Health Sciences, 40014 Jyväskylä, Finland*

ARTICLE INFO

Article history:
Received 9 July 2010
Received in revised form 4 February 2011
Accepted 14 February 2011

Keywords:
Fibromyalgia
Narrative research
Peer support
Rehabilitation

ABSTRACT

Objective: The aim of the present study was to analyse how experiences of peer support were described and reflected upon several years after a group rehabilitation intervention. Moreover, we wanted to learn more about what meanings were ascribed to peer support in the narratives of women with a long history of fibromyalgia.

Method: This was a qualitative study in which narrative life story interviews of 20 women with fibromyalgia were collected and analysed to elicit the impact of peer support in their lives.

Results: We identified four main domains of experienced peer support; permission to talk, need of information, reciprocity and self-evaluation through comparison. The meanings ascribed to peer support were mainly positive, although the participants also expressed thoughts about fear of future, hopelessness and mental health issues.

Conclusions: Long-term fibromyalgia patients saw peer support as an impetus to an ongoing process of reconstruction of identity, illness acceptance and coping with fibromyalgia.

Practice implications: In addition to up-dating their knowledge about fibromyalgia and its treatment, *long term patients* may need arenas where they can share and compare their experiences to those of other patients with a long history of fibromyalgia.

1. Introduction

Fibromyalgia is a chronic, painful condition of unknown origin affecting approximately six million people in Western Europe alone. The prevalence is estimated to be 2.9–4.7% in the general population; women are 5–9 times more often affected by fibromyalgia than men, and women suffer more often from several co-morbid symptoms than men [1,2]. In spite of extensive research during the past two decades, no cure for fibromyalgia is yet known. Currently, aerobic exercise, medication and cognitive-behavioural therapy or a combination of these are recommended to alleviate the symptoms and to enhance overall functioning [3,4].

In addition to intense, widespread musculoskeletal pain and tenderness, patients with fibromyalgia often suffer from several overlapping symptoms like fatigue, depression, morning stiffness and general malaise [5,6]. However, the symptoms do not usually "break out", but evolve slowly over weeks or months, becoming more intensive and disturbing with time. The early symptoms do not seem to make any sense as they come and go unexpectedly and the location of the pain changes from one day to the next. After the initial relief that the diagnosis provides, the feeling of stability is replaced by uncertainty over the future [7–9]. Chronic illness can be seen as a biographical disruption where the earlier taken-for-granted assumptions of self, normality and health need to be re-evaluated [10,11]. In fibromyalgia, the patients have to come to terms with the 'new' painful body instead of the former 'silent' body and therefore, they confront the need to restructure their life and identity [12–14].

Research suggests that peer support provided by others who are or have been in a similar situation can help patients make sense of the illness and thus enhance learning to live *with it* and *despite* it [15–18]. Peer support is based on understanding another's situation through the shared experience of illness, which also distinguishes peer support from other types of social support, such as support from family, friends or health professionals [19]. Dennis [20] describes three theoretical models of the impact of peer support on perceived well-being. In the direct effect model, peer

---

[*] Corresponding author at: Satakunta University of Applied Sciences, Faculty of Health Care and Social Services, Maamiehenkatu 10, 28500 Pori, Finland.
Tel.: +358 44 7103768.
E-mail addresses: merja.sallinen@samk.fi (M. Sallinen), marja.kukkurainen@phnet.fi (M.L. Kukkurainen), liisa.peltokallio@sport.jyu.fi (L. Peltokallio).

0738-3991/$ – see front matter © 2011 Elsevier Ireland Ltd. All rights reserved.
doi:10.1016/j.pec.2011.02.011

support affects health by decreasing isolation and by providing understandable information. In the buffering model, peer support buffers the impact of stress by improving coping responses. According to the mediating effect model, peer support influences wellbeing indirectly by providing opportunities for social comparisons and role modelling.

Several studies [21–28] on peer support in conditions related to chronic pain argue for substantial health benefits in terms of decreased pain and depression and increased self-efficacy. Kukkurainen [21] studied participants of a peer group rehabilitation intervention and noticed that fibromyalgia patients who got a lot of peer support or social support from significant others saw their condition more often as being understandable, manageable and meaningful and had higher ratings of quality of life compared to those who had little or no support. The majority of patients experienced the group intervention as beneficial in terms of received support and information. However, about 10% of the patients found participation in a peer group to be strenuous and mentally burdensome and would have preferred a more individual approach.

The pragmatic purpose of the present study was to explore and analyse the experiences related to peer support in order to develop the contents and methods that are used in professionally lead peer groups in fibromyalgia-specific rehabilitation courses. The questions addressed in this study were as follows: how were the experiences of peer group support described and reflected upon in the patients' narratives several years after rehabilitation intervention and what meanings were ascribed to peer support in these narratives.

2. Method

2.1. Narrative approach

Narrative research has roots in the hermeneutic-phenomenological tradition, more specifically in social constructivism. Bruner [29] states that life stories do not ‘‘happen’’ in the real world, but are rather constructed in people's minds. Telling a narrative is a cognitive process that requires re-constructing and reorganising lived experiences in a culturally accepted form. Thus an individual narrative may reveal important issues linking the illness experience, identity and cultural conventions of telling about the illness and its treatment [10,29]. In this study, narrativity is understood both as a method of data collection and analysis and as a way the participants used to construct their realm and to re-interpret their lived experiences.

2.2. Participants

During 1999–2001, 169 fibromyalgia patients participated in rehabilitation courses in the Rheumatism Foundation Hospital in Heinola, Finland. Each course of 10–12 patients was completed in 17–20 days, divided into two or three intensive in-patient periods. Lectures, group discussions, physiotherapy group exercises and individual treatments were included in the programme. However, the emphasis was on education and counselling in a multi-professional setting instead of treatment of the symptoms. The daily programme provided several possibilities for sharing experiences with the other participants, and the participants were encouraged to continue discussions in their leisure time during the rehabilitation course as well as after it [21]. The present narrative study is part of a multi-method follow-up study of these patients that was launched in 2007 to expand the knowledge of the long-term effects of fibromyalgia on functioning and health-related quality of life.

The local ethical committee approved the study design and methods of the present study. A letter with information on the study and a consent form were sent in May 2007 to all eligible participants of the rehabilitation courses (n = 152/169); 47 of the respondents gave written informed consent to participate in the narrative interview study. Following the idea of Curtis et al. [30], we used age, professional background and location as inclusion criteria to reach a rich variety of participants from different parts of the country. Finally, a purposive sample of 20 women aged 34–65 years (mean age 54) participated in the interview study. The participants reported pain duration of 10–30 years, and the majority of them had been diagnosed with fibromyalgia in the late 90 s. The sampling and characteristics of the participants are described in our earlier article [31].

2.3. Data collection

We used a narrative interview method to collect the data. The first author (MS) conducted all the interviews in August–October 2007 at a time and place chosen by each interviewee, in most cases at their home. At the beginning of an interview, she reminded the participant of the purpose of the study and emphasized the participant's right to withdraw from the study at any point. She also asked if recording the interview was allowed and explained that the recording device could be switched off if it was found disturbing.

The interviews followed the idea of three phases introduced by Rosenthal [32] and Wengraf [33]. The interview started with a short instruction:‘‘Tell me your life story. You can start from the point of your choice and include whatever you find necessary’’. Then the researcher invited the participant to reflect upon the life story through questions that emerged from the story. In the third phase, the researcher used informal discussion to end the interview. This gave the participant a possibility to comment on her own account and to ask any questions from the researcher.

2.4. Data analysis

We analysed the data stepwise applying the ideas of Polkinghorne [34], Labov and Waletsky [35] and Riessmann [36]. The first author (MS) transcribed the recorded data verbatim and read the transcripts several times in order to understand the life stories as a whole. In the second stage of the analysis, we divided the stories into identifiable episodes and organized the episodes chronologically to reconstruct a core story of each interview. However, only the episodes where peer support or social support from family or friends was discussed were included in the analysis of this study. In the final stage, we analysed the data in detail, moving back and forth between the episodes and the core stories.

The women's experiences of peer support fall under four themes. The first two describe mainly the first encounters with the peer group: ‘permission to talk’ and ‘need for experiential knowledge’. Two additional themes describe peer support as a process that emerged during the rehabilitation course but continues even today. These are named ‘reciprocity’ and ‘self-evaluation through comparison’. All the participants commented spontaneously on the experiences of peer support and although quotations from interviews of only nine women are used here, thoughts and comments parallel to these could be heard in the interviews of other participants, too.

In the following examples all personal identifiers have been removed or disguised so that the persons described are not identifiable and cannot be identified through the details of the story. In the excerpts, pausing is marked with dots (. . .) and emphasis of words with underlining. Some additional information is provided in square brackets [e.g. context].

3. Results

3.1. Permission to talk

The majority of the women in the study had suffered from intense widespread pain and other symptoms for years or even decades before fibromyalgia diagnosis was confirmed. In the narratives, the encounters with peers appeared to be a significant turning point after struggling with uncertainty and negative attitudes for years. For many women the rehabilitation course was the first possibility to meet others with the same diagnosis. The importance of peer encounters is highlighted in the following excerpt:

> Oh, it was such a wonderful time... I don't know if I would be here without that period... I was as exhausted as anyone can be, both physically and mentally... and just waited to get there... and there we had this peer group of ten people... it was like a second heaven for me... (Anita, 58)

The women explained that they were not able to tell about their pain and other symptoms at home or at work, because it was seen as 'whining for nothing'. Moreover, they did not want to burden their family and colleagues by constant pain-talk, but kept it to themselves. The experience named here as 'permission to talk' was the most rewarding experience during the rehabilitation course; they were allowed and encouraged to talk about the symptoms and what consequences they had for daily life. At the rehabilitation course the women found peers who not only listened, but who were genuinely interested in their accounts.

> You know, it is so hard to have this illness... but it kind of grew smaller when I noticed that others have it too and that I may talk about it... you see... earlier when I had severe pains I just kind of shrank into myself...but there you were finally allowed to talk about it aloud with others... (Leena, 46)

3.2. Need for experiential knowledge

For most of the women the main motivation to apply for the rehabilitation course had been the need for more information about fibromyalgia. In the narratives, many women compared their diagnosis to rheumatoid arthritis. Everyone had some understanding and knowledge of rheumatoid arthritis, whereas fibromyalgia as a word did not give any information about the illness in question. The participants experienced fibromyalgia as an 'unreal disease' due to lack of cure, vagueness of symptoms and negative attitudes of both lay people and health professionals. The following excerpt elucidates this issue:

> All the information I got was good, of course... but I think it was this talking with others... you see, I had said earlier [before diagnosis] that fibromyalgia is an "illness" in inverted commas, not a real one... and it was difficult for me to change this perception... but there I began to understand better... discussions with the others...those were really important... these symptoms are real, and not just something imaginary... (Sirpa, 61)

Some participants had longer experience with fibromyalgia and were able to share their own knowledge of different medications or other treatment modalities in the peer group. The peers also gave practical advice for managing the difficulties in everyday life, such as how to deal with sleeping problems or how to cope with the constant pain. Although information given by professionals was highly appreciated, the experiential knowledge of peers was perceived as essential to make the information easier to understand and digest. Päivi tells about her expectations and experiences:

> I had thought that it is a specialist hospital for rheumatic diseases, so they will at least know what this is all about... and then I thought that it is good to see others... to hear how they have managed with things and how they have treated themselves... and I got all this... I learned how fibromyalgia is studied widely all over the world and that it really is a disease... not just something obscure... and that there are practical things that help you cope with it... (Päivi, 65)

In the narratives, many participants expressed their need for updating their knowledge on fibromyalgia. Their functional capacity and work ability had changed due to other health problems and ageing, and they were eager to get more information about treatment options and to share their experiences with others with a long illness history. Especially women living in rural areas perceived participation in public lectures or group discussions provided by local support groups to be too time-consuming to be an option in the search for up-dated information.

3.3. Reciprocity

Reciprocity was an important element in peer support in the accounts of the participants. It included the idea of receiving support, comfort and understanding and giving those to others. The earlier experience of being odd, strange or an outsider was displaced by an experience of belonging to a group and not being alone with one's problems. Not only was the similarity in the illness process identified, but also similarities in life events in general. This is elucidated in the following quotation:

> ... at that time my life situation was... you know, husband was drunk 24/7 and I was constantly worried and scared ...it was terrible... then you surprisingly hear that someone else has experienced the same things in her life or in her body...she knows what you mean... almost without words... (Ruut, 60)

For many women reciprocity was also the main motivation for participating in the interview study. The women expressed their gratitude for the peers they had met in their early days with fibromyalgia and hoped that sharing their own experiences would help others in the future. Some of the women had participated in a local fibromyalgia group as a peer supporter after the rehabilitation course because they thought it was important for the 'beginners' to see others who have managed to cope with the illness and to give hope. However, as time went by, the support groups no longer fulfilled their needs, because they felt either too well or too sick to benefit from the group. The following extract sheds light on this issue:

> ...but after a couple of years I felt that I did not belong there [voluntary peer group] anymore...I did not have anything to give... I thought that I don't want to go there bragging about my recovery, because many of them will never recover, quite the opposite...so I withdrew from the association... (Leena, 46)

Marjukka's account gave an opposite perspective on reciprocity. She had been taking care of a family member with a severe illness for years and at the time of the rehabilitation course, the situation turned critical. She tells about her inability to accept the support that was offered to her during the rehabilitation course.

> . . . I know that many of them became friends. . . but I did not belong there.. I was so alone. . .an outsider. . . I think they just did not know how to approach me with all these problems and what to say to me. . . they did try to comfort me when there was a turn for the worse. . .[crying]. . . brought a candle and all . . .but they did not come close enough. . . and I was not able to . . . receive. . . I was so exhausted. . . I could not accept the support that I was offered. . . (Marjukka, 51)

3.4. Self-evaluation through comparison

As the rehabilitation course took place in a rheumatology hospital, the patients with fibromyalgia also met patients with other rheumatoid diseases. The women described meeting others with even more severe symptoms or with a demanding life situation as a mirror that helped them see their own life in a new light. Helena's anecdote pinpoints the comparison between fibromyalgia and rheumatoid arthritis:

> One day we went to have coffee in the hospital cafeteria. An elderly lady with very bad rheumatoid arthritis, you know. . . all joints twisted and all. . . walking with great effort . . . came to sit with us and asked us "what's your disease?" and we told that we had fibromyalgia. . . she sighed with pity in her voice and said "oh dear, that is a terrible disease!" . . . You see. . . it was funny because we had just thought that she had the biggest problems of us all. . . (Helena, 45)

Interestingly, all the participants expressed that their own situation was less demanding compared to some others in the fibromyalgia peer group. Especially mental health problems that were noticed in others forced the women to reflect on their own situation. Many women positioned themselves as 'mentally strong' or 'resourceful' in comparison to 'those with depression'. On the one hand, the pain as such was perceived bearable but with fatigue and depression, it seemed to be beyond control. On the other hand, meeting others with more severe symptoms was seen as a motivation for taking better care of oneself. Sanna explains:

> . . . There were many who were in really bad condition and who had problems with mental health. . .I could not help thinking if that is to be my destiny, too. . . of course sometimes when you are really. . . [in pain]. . .you find yourself thinking when walking along the riverbank. . .how easy it would be to jump into the water. . .but then you just think of all the good things you have. . . I have decided that I will not let it get so bad that it wipes me out. . .I have managed to struggle and win so far. . . (Sanna, 46).

4. Discussion and conclusions

4.1. Discussion

Fibromyalgia has a major impact on peoples' lives, particularly on how they view themselves and how they think others view them. As Aldrich and Eccleston [37] state, what is important about chronic pain is not the pain itself but the threat it causes to self-identity. In the narratives of the present study the women viewed the encounters with peers as a significant turning point in their lives: they were finally heard, believed and accepted. The interviewed women positioned themselves as 'hardworking' and 'work-oriented' to emphasize the contrast to the general attitude they confronted daily. Werner et al. [38] described the 'whispering voices' as a presentation of the medical discourse where women with chronic pain are bound to repeatedly convince themselves and professionals about the legitimacy of their symptoms. From the identity perspective, it is essential that one can trust that the bodily experiences are true and not imaginary and that the experiences are not underrated or discredited by others. One of the participants put it clearly: *In a peer group you don't need to pretend to be healthier than you are, but you can be the one you are.* Similarly, LaChapelle et al. [17] saw pain acceptance as a continuous daily process, in which the peer group was seen as a 'safe haven' where frustration and anxiety could be expressed without burdening the family. This distinction between peer support and social support from family or colleagues could be heard in the narratives of this study, too.

Reflecting on the concept analysis of Dennis [20], in our results the themes 'permission to talk' and 'need for experiential knowledge' represent the direct effect model, where peer support increases wellbeing by strengthening the sense of belonging to a group as well as by expanding access to understandable information. Stressful events and experiences can be re-evaluated and redefined and new problem-solving methods can be found through 'reciprocity', as described in the buffering effect model. The elements of the mediating effect model, in turn, could be recognized in the experience named here as 'self-evaluation through comparison', where wellbeing is indirectly influenced through role modelling, social comparison and cognitive restructuring [20].

According to our findings, reciprocity is a central element in peer support of patients with fibromyalgia. However, reciprocity requires resources to give and receive emotional support. The example of 'Marjukka' indicates that not all patients are ready to discuss their problems or to receive support from their peers. Health professionals need to develop their own skills in listening to complicated and chaotic life stories and to develop methods to coach patients in strengthening their abilities to receive help and support. Moreover, McCracken and Zhao-O'Brien [39] state that when the patients allow themselves to experience some of the unwanted psychological experiences of illness instead of trying to control these, they are more likely to function better and suffer less. Therefore, it may be essential that in addition to updated information on fibromyalgia, health professionals also bring controversial issues purposively into peer group discussions and thereby help the patients to encounter future difficulties. Mead et al. [19] pointed out that peer support should initiate a process of building affiliation but should not end there. We state further that without the experience of reciprocity and mutual support the feeling of otherness cannot be overcome.

In concordance with Kukkurainen [21], in this study the meanings ascribed to peer support were mainly positive: daring to be oneself, feeling a sense of community and enhancing empowerment through validation of one's experiences. However, seeing others with more severe functional disabilities or depression also raised some contradictory thoughts; anxiety related to the future, occasional hopelessness and despair and fear of mental health problems. Since one motive for participation in the interviews was the wish to help others by sharing one's own experiences, it is possible that the participants did not want to bring adverse experiences of peer support into discussion. It is also possible that people with negative experiences of group rehabilitation in general opted out of the follow-up study.

The rationale behind the narrative approach in the present study was to hear stories that have not been given a voice before. The rigour of qualitative research can be evaluated through reflexivity and transparency as well as transferability of the research process [40]. In this study, the interviewer made conscious efforts to convince the participants that the legitimacy of the story was not questioned and to indicate active listening and empathy. As the participants voluntarily included also sensitive and intimate life events in their stories, the interviewer was obviously perceived as reliable and easy to approach. Many of the participants described the interview as an interesting and empowering experience and expressed their gratitude for being allowed to tell 'the whole story'. The interviews were conducted and transcribed by one researcher; the context and atmosphere of each interview could thus be used as additional information in the preliminary analysis. The findings were discussed and elaborated with the co-authors to reinforce validity of the results. However, we appreciate the subjectivity of the analysis: other researchers might find different aspects in the given data.

Whilst narrative research does not aim to generalize the results to a wider population or convey causalities, it may highlight issues that are relevant to the patient group in question [40]. We were not able to recruit any men to this study, which can be considered as a major limitation of the study. However, because the majority of patients suffering from fibromyalgia are women in midlife, we believe that the results may have relevance in other situations and settings with fibromyalgia patients. It is also possible to compare these results to those of other conditions, where the cause and course of the illness are controversial. Our findings regarding the importance of peer support in validation of the illness experience and legitimating the symptoms are consistent with results from low back pain [25], chronic fatigue syndrome [26], pelvic pain [27] and medically unexplained symptoms [28].

4.2. Conclusions

Peer support may function as an impetus to an ongoing process of reconstruction of identity, illness acceptance and coping with fibromyalgia. The experience of reciprocity seems to be essential to extend the process from 'peer talk' to mutually helpful support. More effort should be focused during rehabilitation interventions on training the patients to strengthen their ability to receive support in difficult life situations.

4.3. Practical implications

The pragmatic purpose of this study was to develop methods and contents of fibromyalgia-specific group interventions. Even if the patients have a diagnosis, they often experience being 'not-heard' or 'not-believed' in their daily encounters with other people. The results of this study imply that long-term patients with fibromyalgia need arenas where they can listen and learn from each other in addition to learning from professionals. Up-dating knowledge of fibromyalgia and its current treatment is beneficial in rehabilitation interventions for chronic fibromyalgia patients, but it is equally important to create peer groups where the participants can experience reciprocity and where they can share and compare their experiences of functioning to those of other patients with a long history of fibromyalgia.

References

[1] Branco JC, Bannwarth B, Failde I, Carbonell JU, Blotman F, Spaeth M, et al. Prevalence of fibromyalgia: a survey in five European countries. Semin Arthritis Rheum 2010;39:448–53.

[2] Yunus MB. Fibromyalgia in men: comparison of clinical features with women. J Rheumatol 2000;27:485–90.

[3] Carville S, Arendt-Nielsen S, Bliddal H, Boltman F, Branco JC, Buskila D, et al. EULAR recommendations for the management of fibromyalgia syndrome. Ann Rheum Dis 2008;67:536–41.

[4] Häuser W, Thieme K, Turk DC. Guidelines on the management of fibromyalgia syndrome – a systematic review. Eur J Pain 2010;14:5–10.

[5] Arnold L, Crofford L, Mease P, Burgess S, Palmer S, Abetz L, et al. Patient perspectives on the impact of fibromyalgia. Patient Educ Couns 2008;73:114–20.

[6] Bliddal H, Danneskiold-Samsøe B. Chronic widespread pain in the spectrum of rheumatological diseases. Best Pract Res Clin Rheumatol 2008;21:391–402.

[7] Aaron LA, Buchwald D. Chronic diffuse musculoskeletal pain, fibromyalgia and co-morbid unexplained conditions. Best Pract Res Clin Rheumatol 2003;17:563–74.

[8] Sim J, Madden S. Illness experience in fibromyalgia syndrome: a metasynthesis of qualitative studies. Soc Sci Med 2008;67:57–67.

[9] Mannerkorpi K, Kroksmark T, Ekdahl C. How patients with fibromyalgia experience their symptoms in everyday life. Phys Ther Res Int 1999;4:110–22.

[10] Bury M, Chronic illness as biographical disruption. Sociol Health Ill 1982;4:167–82.

[11] Bury M. Illness narratives: fact or fiction? Sociol Health Ill 2001;32:263–85.

[12] Madden S, Sim J. Creating meaning in fibromyalgia syndrome. Soc Sci Med 2006;63:2962–73.

[13] Sim J, Smith MV. The sociology of pain. In: French S, Sim J, editors. Physiotherapy: a psychosocial approach. Butterworth-Heinemann: Edinburgh; 2004. p. 117–39.

[14] Crooks V, Understanding. embracing, rejecting: women's negotiations of disability and categorizations after becoming chronically ill. Soc Sci Med 2008;67:1837–46.

[15] Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide, which other supportive relationships do not? The experience of peer support groups for people with cancer. Soc Sci Med 2006;62:2565–76.

[16] van Uden-Kraan C, Drossaert C, Taal E, Seydel E, van der Laar M. Participation in online patient support groups endorses patients' empowerment. Patient Educ Couns 2009;74:61–9.

[17] LaChapelle D, Lavoie S, Boudreau A. The meanings and process of pain acceptance. Perceptions of women with arthritis and fibromyalgia. Pain Res Manage 2008;13:201–10.

[18] Colella T, King K. Peer support. An under-recognized resource in cardiac recovery. Eur J Cardiosvasc Nurs 2004;3:211–7.

[19] Mead S, Hilton D, Curtis L. Peer support: a theoretical perspective. Psychiatr Rehabil J 2001;25:134–41.

[20] Dennis C-L. Peer support within a health care context: a concept analysis. Int J Nurs Stud 2003;40:321–32.

[21] Kukkurainen ML. Fibromyalgia patients' sense of coherence, social support and quality of life. Dissertation. University of Oulu; 2008 [English abstract].

[22] Franks H, Cronan T, Oliver K. Social support in women with fibromyalgia: is quality more important than quantity? J Commun Psychol 2004;32:425–38.

[23] Lopez-Martinez A, Esteve-Zarazaga R, Ramirez-Maestre C. Perceived social support and coping responses are independent variables explaining pain adjustment among chronic pain patients. J Pain 2008;9:373–9.

[24] Evers A, Kraaimaat F, Geenen R, Jacobs J, Bijlsma J. Pain coping and social support as predictors of long-term functional disability in early rheumatoid arthritis. Behav Res Ther 2003;41:1295–310.

[25] Corbett M, Foster N, Ong BN. Living with low back pain – stories of hope and despair. Soc Sci Med 2007;65:1584–94.

[26] Larun L, Malterud K. Identity and coping experiences in Chronic Fatigue Syndrome: a synthesis of qualitative studies. Patient Educ Couns 2007;69:20–8.

[27] McGowan L, Luker K, Creed F, Chew-Graham C. 'How do you explain a pain that can't be seen?': the narratives of women with chronic pelvic pain and their disengagement with the diagnostic cycle. Brit J Health Psychol 2007;12:261–74.

[28] Nettleton S. 'I just want permission to be ill': towards a sociology of medically unexplained symptoms. Soc Sci Med 2006;62:1167–78.

[29] Bruner J. Life as narrative. Soc Res 2004;71:691–710.

[30] Curtis S, Gesler W, Smith G, Washburn S. Approaches to sampling and case selection in qualitative research: examples in the geography of health. Soc Sci Med 2000;50(7–8):1001–14.

[31] Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M. Women's narratives on experiences of work ability and functioning in fibromyalgia. Musculoskelet Care 2010;8:18–26.

[32] Rosenthal G. The healing effects of storytelling: on the conditions of curative storytelling in the context of research and counselling. Qual Inq 2003;9:915–33.

[33] Wengraf T. Qualitative research interviewing: biographic narrative and semi-structured methods. London: Sage; 2001.

[34] Polkinghorne D. Narrative knowing and the study of lives. In: Birren J, et al., editors. Aging and biography: explorations in adult development. New York: Springer; 1996. p. 77–100.

[35] Labov W, Waletzky J. Narrative analysis: oral versions of personal experiences [reprint from 1967]. In: Bratt Paulston C, Tucker G, editors. Sociolinguistic: the essential readings. Oxford: Blackwell; 2003. p. 74–104.

[36] Riessman C. Analysis of personal narratives. In: Gubrium J, Holstein J, editors. Handbook of interview research: Context & Method. Sage: Thousand Oaks; 2001. p. 695–707.

[37] Aldrich S, Eccleston C. Making sense of everyday pain. Soc Sci Med 2000;50:1631–41.

[38] Werner A, Widding-Isaksen L, Malterud K. 'I am not the kind of woman who complains of everything': illness stories on self and shame in women with chronic pain. Soc Sci Med 2004;59:1035–45.

[39] McCracken L, Zhao-O'Brien J. General psychological acceptance and chronic pain: there is more to accept than the pain itself. Eur J Pain 2009. doi:10.1016/j.ej.pain.2009.03.004.

[40] Malterud K. Qualitative research: standards, challenges and guidelines. Lancet 2001;358:483–8.

IV

FATIGUE, WORRY AND FEAR – LIFE EVENTS IN THE NARRATIVES OF WOMEN WITH FIBROMYALGIA

by

Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M & Anderberg
UM, 2012

Health Care for Women International. In press.

Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M & Anderberg UM

Fatigue, worry and fear – Life events in the narratives of women with fibromyalgia

Abstract

In this article we explored narrated life stories of twenty women with a long history of fibromyalgia to reach a deeper understanding of how people interpret the causes and consequences of different life events and illness experiences. Based on narrative analysis we identified three model narratives that illustrate the different life courses of women with fibromyalgia. In addition, we described a counter-narrative that questions the existence of fibromyalgia as a chronic disease. This narrative study gives insights to the invisible symptoms and unheard experiences that are associated with fibromyalgia. Hence, this study contributes to the ongoing discussion on the etiology and maintenance of fibromyalgia.

Introduction

During the past decade there has been a growing interest in the narratives of people with chronic illnesses. In social and health sciences, narratives have been used to illustrate patients' illness experiences, for example in advanced cancer (Coyle, 2004), low back pain (Vroman,Warner;& Chamberlain, 2009; Campbell & Cramb, 2008) or chronic regional pain (McGowan, Luker, Creed & Chew-Graham, 2007; Lonardi, 2007). Regarding fibromyalgia, life stories have previously been explored in terms of identity transformation (Åsbring, 2001) and biographical disruption (Richardson, Ong & Sim, 2006), as well as in terms of work ability and fatigue (Sallinen, Kukkurainen, Peltokallio & Mikkelsson, 2010; Sallinen, Kukkurainen, Peltokallio & Mikkelsson, 2011). However, fibromyalgia patients' life-stories as such have rarely been studied. We wanted to learn more about how fibromyalgia patients interpret their life events and illness experiences and how they explicate these experiences in a life story. In this article, we explore the structure and content of narrated life stories of women with fibromyalgia to elucidate the different life courses patients with fibromyalgia may have.

Fibromyalgia, stress and live events

Fibromyalgia is a significant health problem as well as economic burden in all contemporary societies. In a recent epidemiological study in five European countries, the overall prevalence of fibromyalgia in a general population was 2.9-4.7%, which means that there are more than six million fibromyalgia patients in Western Europe alone. The majority of fibromyalgia patients are women in mid-life, and the prevalence increases with age. (Branco et al., 2009.) Fibromyalgia is characterized by fluctuating, widespread musculoskeletal pain, fatigue and general malaise. The patients also suffer from a variety of other symptoms, such as persistent headache, morning stiffness, sensory sensitivity, depression or impairment of memory and concentration skills. (Wolfe et al., 2010; Arnold et al., 2008.) Patients find fibromyalgia emotionally distressing and difficult to understand, and they do not expect medical treatments to be effective. Inability to understand the experienced symptoms seems to increase anxiety, desperation and tendency to catastrophic thinking. (van Ittersum,van Wilgen, Hilberdink, Groothoff & van der Schans, 2009; van Wilgen, van Ittersum, Kaptein & van Wijhe, 2008.)

The precise pathophysiology and etiology of fibromyalgia are yet unknown, but according to the current paradigm, dysfunctions of the autonomic central and peripheral nervous systems, genetics and alterations of the stress regulatory system may explain increased sensitivity to pain and stress in this patient group (Bliddahl & Danneskiold-Samsøe, 2008; Buskila, 2007; Yunus, 2007). Although major stress or adverse life events do not cause fibromyalgia as such, they may account for increased susceptibility to alterations of the stress-response system (Nicholl et al., 2009; Dadabhoy, Crofford, Spaeth, Russel & Clauw, 2008; Gupta & Silman, 2004). Research suggests that especially traumatic experiences in childhood or adolescence or long-term psychological and emotional burden may increase vulnerability to chronic widespread pain, depression and fatigue, and hence perpetuate the chronicity of fibromyalgia symptoms (Jones, Power & Macfarlane, 2009; McBeth et al., 2007; Bailey, Freedenfeld, Sanford Kiser & Gatchel, 2003; Hatcher & House, 2003; Lampe et al., 2003).

In a study by Anderberg, Marteinsdottir, Theorell and von Knorring (2000), up to 48% of fibromyalgia patients reported at least one negative life event in childhood, compared to 24% by healthy controls. Fibromyalgia patients had also experienced physical or mental abuse, financial problems and illness or death of a close relative in adulthood significantly more often compared to controls. Moreover, fibromyalgia patients experienced the impact of adverse life events to be more negative and more severe than their healthy counterparts. (Anderberg et al., 2000.) In a recent study, however, only two traumatic experience types – sexual and physical abuse– were associated with the onset of fibromyalgia, whereas other major life stressors, such as serious illness, divorce or miscarriage were not (Haviland, Morton, Oda & Fraser, 2010). Kukkurainen (2006) on the other hand noticed that in patients with fibromyalgia the number of life events correlated negatively with a sense of coherence, which is an important health resource. The more severe life events they had, the lower was the sense of coherence.

However, we must bear in mind that the majority of fibromyalgia patients have presumably not experienced dramatic life events, but have rather lived a life with joys and vicissitudes similar to any other people. Therefore, the purpose of the present study was to reach a deeper understanding of how people with a long history of fibromyalgia express and interpret the causes and consequences of different life events and illness experiences from the perspective of a life story. In particular, we were interested in how the life stories were constructed, and whether or not different types of storylines – so-called model narratives – could be identified from the data.

Methodology

Narrative approach

Illness narratives as such serve several purposes: to construct illness experience, to construct life history, to make illness understandable and to collectivize the illness experience. Illness narratives do not have a clear and foreseeable end; they build upon the possibility of different endings. In that sense illness narratives are constantly renegotiated depending on changes in the illness process or on the situations or settings where they are told. (Hydén,1997.) Bruner (2004, 1991) states that life stories do not "happen" in the real world, but are constructed in people's minds, and are therefore both subjective and context-bound. Each time a life story is told, the person telling it can find new or additional meanings of events depending on the context and the audience. Riessman and Speedy (2007) in turn differentiate narratives from other forms of discourse in terms of *sequence* and *consequence,* through which the events are selected, connected and evaluated as meaningful for the particular listener. In research interviews the impact of the interviewer in the narrative process is hence inescapable (Randall, Prior & Skarborn, 2006; Bruner, 2004; Riessman, 2001). In this study the participants are understood as active agents, who are not only describing their life events, but who are also actively negotiating and reconstructing their life-story by choosing and interpreting the events, and by emphasizing different aspects of their experiences.

Study design and participants

We conducted individual narrative interviews as part of a wider follow-up study of the participants (n=169) of fibromyalgia-specific rehabilitation courses that were completed during 1999-200 in a rehabilitation hospital in Finland. The regional offices of the Social Insurance Institute (SII) selected the course participants based on application and doctor's referral. SII was also responsible for covering the costs of rehabilitation. The 17- to 20-day courses were conducted in groups of 10-12 participants, divided into two or three intensive in-patient periods within six months. The program comprised lectures by various specialists, group discussions, exercise and some individual treatments, but the emphasis was on education and counseling instead of treatment as such.

In 2007, we recruited a purposive sample of twenty women with fibromyalgia, aiming at maximal variation in terms of age, professional background and location for narrative interviews. The sample consisted of women aged 34-65 years (mean age 54) from both urban and rural areas of the country. Their professional background can be considered to be typical to Finnish women: health care and social work in different settings, teaching, office or industrial work. The reported symptom duration ranged from 10 to 30 years (mean 17 years), but the majority of the participants were not diagnosed with fibromyalgia until the late 90s.

The study design and methods were approved by the local ethics committee. Furthermore, we asked and obtained a written informed consent from the participants before arranging the interviews. The first author (MS) conducted all the interviews at a place and time convenient for the participants, in most cases in their homes. At the beginning of each interview the researcher explained the context and the purpose of the study and reminded the interviewee of the right to withdraw from the study at any point. She also asked if recording the interview was allowed and assured that the recording device could be switched off if the interviewee found it disturbing.

Collection and analysis of the data

The interviews followed the ideas introduced by Rosenthal (2003) and Wengraf (2001) who suggested opening the interview with a spontaneous narrative and then continuing with open questions to expand the narrative. In this study the interviewer gave a short instruction to prompt spontaneous story telling: ”Tell me your life story, you can start from the point of your choice and include whatever you find necessary”. The interviewer made conscious efforts to show active and empathetic listening and did not interrupt the narrative process until the interviewee signaled that she had finished. In the second part of the interview, the interviewer asked questions emerging from the account to expand and deepen the story telling. Typical questions were: ”What happened after you…?” or “Can you give an example of…?” The interview session ended with an informal discussion where the interviewee was encouraged to ask any questions concerning the research project or current treatment modalities of fibromyalgia or to comment on her own contribution. This also gave the interviewer a possibility to make sure that she was at ease, since reminiscence of earlier life events might be perceived as mentally distressing. The length of the interviews varied from 2 to 4 hours; about 2.5 hours was typically used for the whole session.

The analysis of the data was inspired by the narrative analysis and episodic reading introduced by Polkinghorne (1996) Labov and Waletsky (1967/2003) and Riessmann (2001). The interpretation of the data begun already during the interviews where the interviewer was to be sensitive and alert to notice the key points as well as the gaps in the spontaneous narrative that needed to be filled in the second part of the interview. The interviewer listened to the recorded material of each interview and transcribed the data verbatim within the following few days.

In the first stage of the analysis the orientation was towards the content of the data: *what* were the interviewees talking about? We listed the topics and subtopics that emerged from the data for further analysis. In this study, however, our main focus was on the structure of the narrative i.e. *how* was the story told? In most cases the life stories were not represented as a single story, but rather as a series of small, parallel episodes. In the second stage of the analysis we identified these episodes and organized them chronologically in order to see the links between different events and experiences and to reconstruct a condensed core story of 1-2 pages of each life story.

In the final stage of analysis we aimed at narrative emplotment: finding common storylines or plots that combine the structure and content of several life stories to a model narrative. To do this, we re-analyzed and compared the storylines and episodes of all 20 interviews to find recurrent structures in the narratives. We also explored the rhetorical means that the participants used to signal the beginning or end of an episode (*entrance and exit talk*, see Riessmann 2001) or to point out the subject position that they took when telling about different events (Hydén, 2005). The analysis process is illustrated in Figure 1.

[insert Figure 1 here]

Results

We found three different model narratives concerning life with fibromyalgia: narratives of ‘mundane life’, ‘cumulative life’ and ‘broken life’. Moreover, we were able to identify a counter-narrative that resists and takes distance from the common ways of talking about fibromyalgia (see Hyvärinen 2008). In the following we illustrate these three model narratives with extracts from interviews with three women respectively, in order to retain the narrative nature of the data. We selected these particular women (Maire, Riitta and Marja) because they, more clearly than others, approached their life events from several different angles, thus producing versatile narratives for analysis. In each section of the findings the pseudonyms of other participants with predominantly similar narratives are mentioned in brackets. Although the details of the life stories differ individually from those presented here, the narratives of 18 women can be understood as variations of the three model narratives. The remaining two life stories can be perceived as presentations of a counter-narrative questioning the existence of fibromyalgia as a disease in general.

In the following examples we use pseudonyms to protect the integrity and identity of the participants. In the quotations we marked pausing in speech with dots (...) and emphasis of words with <u>underlining</u>. We also provide some additional information in square brackets to help understand the contents of the quotation [e.g. context].

Mundane life

The storyline of the life stories of five women *(Maire, Pirkko, Linda, Sari and Heli)* describe a 'mundane life'; a life with no dramatic turns, but rather an expected life course. We condensed the storylines of these accounts as follows:

1. Expected life course including school, studies, marriage and family life
2. Onset and worsening of pain and fatigue
3. Diagnosis after a lengthy search
4. Rehabilitation course as a source of information
5. Return to work; adaptations of working tasks or hours to improve functioning and work ability

6. Moderate limitations on work ability
7. Positive view on the future

Maire's narrative is an example of 'mundane life'. Maire begins her story by describing her childhood, her family, friends and neighborhood. She uses wordings like 'happy life' or 'safe childhood' when talking about her early years. The following excerpt draws a picture of an expected life course:

> *I had a safe childhood ... there were a lot of kids in our neighborhood… After high school I was interested in working with teenagers, so I studied to become a youth leader, and thought that I would later continue studies in social or education sciences… but then I got my first permanent job here and met my husband…*

At first, participants had paid little or no attention to the waxing and waning symptoms of fibromyalgia, interpreting the pain and fatigue to be caused by e.g. overloading at work or by common flu or some other health problem. Gradually the symptoms became more debilitating and could no longer be considered temporary. The women described the search for diagnosis as a long and frustrating journey, and in many cases it took several years before the diagnosis was confirmed. Maire elucidates this period of life as follows:

> *… I did not know what was bothering me… I just thought that it was the flu and work stress….I was tired all the time and had no initiative…I was enthusiastic about my work, but the pain made me so tired… I did not sleep… I did not realize what it was... I just became more and more tired… Then a friend of mine, a nurse, said that I should go and see a rheumatologist instead of being shunted between doctors year after year… and he gave me the diagnosis right away…*

Many women initially perceived the diagnosis as a relief; finally the suffering had a name. However, over the years they noticed that the diagnosis was not very helpful because often every health complaint they had was seen as a consequence of fibromyalgia and was treated accordingly, which often meant no treatment or medical examination at all. Moreover, the participants perceived fibromyalgia diagnosis as a burden due to the negative attitudes of health care professionals. Maire phrases this politely:

> *The diagnosis was a relief, of course… but this much I must say… later when I went to the health care center or occupational health care to complain about something else… the doctor would not listen but say that it is because of your fibromyalgia... that was frustrating…*

The women searched actively for more information about fibromyalgia and its treatment, although there was little information about fibromyalgia available for the general public in the mid- 90s. Therefore, the participants' main motivation for applying for a fibromyalgia-specific rehabilitation course was search for information. The participants experienced both the lectures and exercises provided by professionals and the discussions with other patients with the same illness as important and beneficial in terms of legitimating the symptoms and increasing coping skills and self-care resources. Meeting others whose situation was even worse helped to put one's own situation to a new perspective, like in the following excerpt:

> *I had thought that I was miserable…but when comparing to the others, I noticed that I was actually doing pretty well…I felt sorry for some of the people there… maybe they had received the diagnosis too late, they were in such a terrible condition…*

The participants described warmly the support and help they had received from their family, friends and colleagues when their functioning began to deteriorate. They had been able to share their domestic work load as well as their duties at work, and felt that their motives to do so were not questioned. Maire sheds light on this issue:

> *My family has been great… the children are living on their own now, but they come home to help me… even without asking… and he does part of the heavy cleaning work…they understand… I have a good job… my boss is very understanding; he often reminds me that I should take it easier…*

At the time of the interviews, all the women with 'mundane life' continued in a paid work role and were able to participate in various hobbies and other activities. Some adaptations were made concerning work tasks or working hours to support the work ability in a longer perspective. The women described their current work ability and functioning to be limited, but expected to be able to live a 'normal life' in the future as well. Maire says:

> *Well, you see… I am like a barometer…* [laughing]*… I always know in my bones when the weather changes… I don't use too much medication, only some mild painkillers occasionally… I have about ten more years at work … And now* [after a 6-month sabbatical] *I feel that I can make it… I really can…*

In summary, women with a 'mundane life' seemed to cope well with their symptoms; they had learned to live with fibromyalgia. The social support from family, colleagues and friends helped them to continue with their normal activities, and although fibromyalgia disturbed their life, it did not have a major impact on the expected life course.

Cumulative life

Seven life stories *(Riitta, Kaisa, Aili, Ulla, Mailis, Anu and Eeva)* were characterized by cumulative daily hassles; i.e. difficulties that everyone encounters now and then and that can normally be tackled. When they appear simultaneously however, one may not have the resources to solve them. The life events could include minor and major difficulties in the family, divorce, work-related problems, starting a new job, financial difficulties or taking care of elderly parents. Each 'cumulative life' narrative was constructed of different combinations of life events, but the development of the storylines was comparable to the following example, which is based on Riitta's story.

1. Normal life including family life, work and hobbies
2. Serious illness and death of a close family member, unemployment and re-education
3. Increase in unexplained pain and fatigue
4. Domestic problems, difficulties finding a job, mother's illness
5. Intolerable pain symptoms
6. Rehabilitation course as 'quitting the rat race'
7. Return to work
8. Fluctuating difficulties in functioning and work ability
9. Retirement

In the 'cumulative life' narratives the onset of fibromyalgia was perceived as a consequence of disruptions in life. Often the life events caused sleeping problems and fatigue in addition to constant worrying. The women drew a picture of a hard-working woman, who would continue with her work and home duties at the cost of her own health and well-being. They described vividly how they muddled their way through difficulties, day by day. The following excerpt illustrates the problems Riitta encountered at the time of the onset of symptoms:

> *… At that time my brother died of cancer, my elderly mother had to be taken care of… I lost my job and started to study for a new degree…my husband was drunk most of the time… there was not too much time to ask how I felt… I just began to wonder, when did I become so lazy, shiftless and feeble... you see I was tired all the time but I could not sleep at all...but it took years before I finally got the diagnosis... and it has been nothing but jubilation ever since...*[laughing]

Riitta uses the wording 'jubilation' ironically to point out the daily difficulties she has today. In the following excerpt she summarizes her current functioning:

> *Fibromyalgia plays all these tricks on you, it makes you stiff and aching... I had been wondering why I needed to go to the bathroom all the time, but then I read somewhere that urinary urgency is part of this, too.... then there are all kinds of...* [symptoms]*; tingling, numbness, swelling, stiffness, and difficulty moving... I am used to the pain, though...but I pray for some help with sleeping…*

In the narratives fatigue was perceived as the most disturbing symptom, because it was so overwhelming, beyond control and often came unexpectedly. Many women described in detail the despair and sinister thoughts they had, especially when their life situation was complicated and the symptoms seemed invincible. The following quote sheds light on this issue:

> *When it* [agonizing pain and fatigue] *lasts long enough one begins to lose hope... one gets desperate… and then anxiety and depression begin to creep up… one thinks about taking pills or something… but realizes that 'I don't have any because I did not want any medication'…and thinks that this will never get any better and that one would be better off dead… …but then when the pain eases, even a little ... one begins to think that it is not that bad after all…those days do not occur often, thank God… but sometimes..*

In this quote Riitta distances herself from the situation by using 'one' instead of 'I'. Moreover, she brings the situation closer to the listener by using the present tense when describing past events and experiences. Also other women used similar rhetorical means, especially when referring to shared, yet individual experiences or difficult life situations.

The rehabilitation course offered an opportunity to rest and concentrate on one's own wellbeing instead of taking care of others. The women referred to the rehabilitation course as 'quitting the rat race' or as 'time of my own'. They met peers whose life situation was even more demanding than their own, which helped them to re-evaluate their life from a new perspective. However, because the life situation continued to be complicated, the benefits of the rehabilitation were in many cases lost in a couple of weeks or months. Riitta reflects on the benefits of the rehabilitation course as well as on her life situation back then:

> *It was of course also important that I was accepted as a patient… until then I was always considered a hypochondriac… or a work dodger… but they took me seriously… but it was even more important to find others who have experienced the same things in their life and in their body… and who*

> *understood almost without words… However, I was worried all the time about things at home … that is perhaps why I could not really enjoy and relax at the rehabilitation course…*

After the rehabilitation most of the interviewees with ‘cumulative life’ returned to work. Maintaining work ability was, however, difficult if the life situation in general continued to be as problematic as before. Over the years work ability deteriorated, and in many cases work history was fragmented by co-morbidities and long sick leaves. At the time of the interviews, five of the seven women were not working due to disability pension or difficulty finding a suitable job in view of their functional limitations. Riitta explains:

> *…When I finished my studies* [mid-90s] *suitable work was not available…later I was considered a job seeker with functional limitations due to fibromyalgia, but with my education and these limitations there were few jobs that I could manage …it was always about looking for the next temporary job… wondering how to pay your bills and whether you are entitled to unemployment or sickness benefits or not… uncertainty was constant, it gnaws away at you, you know … but that ended now in February when I was granted a pension…it was a relief…a big relief…*

At the time of the interviews all the women with ‘cumulative life’ perceived their functioning to be better than a few years earlier due to an easier life situation. However, they saw fibromyalgia as a chronic disease from which one can never fully recover, but has to struggle with for the rest of one’s life. In the following excerpt Riitta elucidates her attitude towards fibromyalgia:

> *You have to be caring enough… and hard on yourself so that you force yourself to get up and moving… You must not ask first thing in the morning what is*

> *aching now…I am often so stiff in the morning that it's difficult to get up, but at least I know I am alive…* [laughing]*… This is not the end of the world… there are others who have much worse diseases than this…*

Broken life

The storylines of six life stories *(Marja, Aino, Eila, Teija, Sisko and Vuokko)* were characterized by dramatic and traumatic life events, such as death of a child or severe physical, sexual or mental violence. We named these 'broken life' narratives. They were emotionally loaded, intensive descriptions of life events that had permanently changed the expected course of life. The condensed storyline of Marja's life story is an example of 'broken life':

1. Marriage at an early age, birth of children
2. Husband's alcohol abuse begins; repeated physical violence and battering for several years
3. Divorce followed by mental violence and threatening
4. Husband moves from the city; sense of relief
5. Onset of fibromyalgia symptoms, diagnosis
6. Limited work ability, depression, exhaustion
7. Rehabilitation course as an escape
8. Experienced disability, several rejected applications for disability pension
9. Disability pension; balancing between functioning and disability

In many accounts describing 'broken life', the beginning was characterized by hesitation or doubts concerning the ability to tell a 'good' story. Marja, for example, started with the phrase "*I am not much of a story teller"*, which was then followed by a coherent and rhetorically vivid account that took almost an hour and a half. In some life-stories the beginning already implied difficulties in later life, such as Eila's very first sentences after the invitation to tell her life story: "*Ok, then it is best to start from childhood..., because I think it explains a lot*... ". Similarly, later in the narratives, dramatic turns in life course were signaled with a 'warning' at the end of the previous episode. Wordings like "*until then everything was fine"* or "*now I will certainly begin to cry"* anticipated the negative events that followed. This is highlighted in the following extract by Marja:

> *... everything went pretty well until then, but then... while I was in the hospital giving birth to my first baby my husband found King Alcohol and began to drink heavily… and with time he became more and more violent and more jealous over me... for five years I was battered by him...uhmmm... at least once a month he beat my brains out...*

Later she continues with a more detailed description of battering and closes the episode with a sentence that reveals the extreme severity of the situation:

> *After the divorce I was always on the alert and always scared…for several years…. because he had said that if he ever saw me with any other man he would shoot me dead… and I believed him…* [silence]

In many cases the first symptoms of fibromyalgia did not break out until after the dramatic life situation was over. In some narratives the time span between the traumatic events and the onset of symptoms could be years or even decades. The onset of fibromyalgia symptoms was perceived as an inevitable result of years of distress. In the following excerpt Marja discusses her views on the onset of fibromyalgia:

> *I strongly believe that my husband's behavior caused it… I had so many sleepless nights during those years of marriage and even after the divorce… and the distress … it certainly has an impact… Even now when I tell about it* [the battering] … *it gives me the creeps… I have that fear and horror so deep inside me… not to mention the physical traumas… lately I have noticed that I have these odd, unexplained headaches and I have been wondering if that is caused by the battering too…*

Moreover, many women revealed that they had not talked about their painful experiences with their friends or colleagues and in some cases not even with their family members. For example, domestic violence was perceived as an issue that was only discussed with health professionals, if at all. The participants explained this decision by not wanting to burden others and by feelings of guilt and worthlessness. The rehabilitation course was for many women an escape or vacation from a difficult and depressing life situation, 'a second heaven' as one of them put it.

All the women with 'broken life' narratives suffered from depression, and none of them were working at the time of the interviews. Marja had applied for disability pension already before the rehabilitation course, but her application had been rejected. In the following extract she reflects on the process:

> *I actually quit working in 1999… I was in such terrible pain and totally exhausted that I decided that this had to stop… but it took four years to get disability pension… it was first denied, and I did not get money from anywhere and nobody told me what to do…I was sent to work try-outs* [as part of vocational rehabilitation] *but after two or three days I was in so much pain that I could barely move… eventually, the psychiatrist prescribed a lengthy sick*

> *leave and later I was granted disability pension, but it was due to depression* [and not due to fibromyalgia]

Loss of control over one's body and one's life in general was a prominent feature in the 'broken life' narratives. Although the traumatic events described in the narratives were different, substantial similarity could be seen in the perceived consequences of the events, such as constant fear, worry and overwhelming fatigue. In these narratives coming down with fibromyalgia did not play a significant role; it was rather seen as an inevitable result of the bodily and mental traumas caused by the unbearable life situation. One of the interviewees put it clearly: *"My body collapsed because my mind could not afford to do so"*.

Counter-narrative

In the narratives of Lea and Laura, the existence of fibromyalgia as a disease or as a chronic disease was questioned. We describe this phenomenon as a 'counter- narrative'. In these life stories the descriptions of pain and fatigue symptoms were similar to those of other participants. However, the connotations of the experiences were different from those explicated by other interviewees

Lea positions herself as a 'former fibromyalgia patient'. She was a victim of severe bullying at her earlier workplace, and sees this as the main reason for her symptoms. In the following extract she reflects on her illness and recovery after changing her work place:

> *There is no other possibility… I was so tense that all my chemistry went upside down… it was such hell of a life, I say… with distress and pain and strong painkillers… then the rheumatologist finally examined me, I had 17 out of 18*

> *tender points.… but I don't have it anymore... now I am completely healthy... of course sometimes I have pains and aches but it is nothing compared to what it used to be... everyone has pain sometimes.... Now that I think about it, I should have left* [the job] *much earlier… but back then I just did not have the resources… at that time I was ready to apply for disability pension, because I saw no other option ... but now the situation has changed completely.... and I expect to be able to continue working until I am 62...*

Lea emphasizes the difference between 'now' and 'back then' and points out the normality of occasional pains and aches (*"everyone has..."*). Furthermore, she refers to disability pension to highlight how difficult the situation was earlier. In the last sentence of the quote Lea draws a picture of another 15 years at work, in contrast to her earlier thoughts of the inevitability of disability.

In Laura's narrative the confrontation with other narratives was even clearer. She had worked in elderly care and had retired after 'full service' about two years prior to the interview. In the following example Laura positions herself as 'healthy but overloaded':

> *I fell and got a shoulder injury ... it was the late 80s… and that pain remained ever since… of course I had to use the other arm more* [at work] *and it also began to ache… the shoulder was operated on last year and now it is fine… of course the pain caused sleeping problems back then, but I never needed a lot of sleep … I used to work in a geriatric ward, which was physically heavy work, because you had to transfer patients, who could not move at all … but I have always enjoyed using my strength, so I did not mind… but maybe during the last years I overloaded myself a bit… now that I am retired, I feel better than ever…*

In the quote above, Laura sees the shoulder injury as the original trigger of her pain, which got worse due to physically demanding work. She also gives other arguments to strengthen her views; the shoulder operation and retirement have led to a non-symptomatic situation. Later she continues:

> *I'm not sure if fibromyalgia really exists… I doubt it… it's probably just another trash-basket diagnosis that the doctors give you when they cannot find anything else; just to get rid of you… I doubt if I ever had it…the symptoms matched, yes…but still… I wonder…*

In this quote in particular, Laura questions fibromyalgia as a disease, and juxtaposes it implicitly to backlog of work in health care, due to which the doctors have little time to go deep into individual patients' problems.

Summary of results

The main characteristics of the three model narratives and the counter-narrative differ from each other in terms of life before symptoms, perceived cause of illness and rehabilitation metaphors as well as in terms of life after rehabilitation and perceived current functioning. However, they all contain and sometimes even focus on the participant's fatigue, exhaustion and perceived distress either as a cause or a consequence of the illness. (Table 1)

[insert table 1 here]

Discussion

It is necessary to address some methodological considerations before a concluding discussion. Firstly, all the participants were interviewed only once. It would have been preferable to conduct several interview sessions to better reach different aspects of life, but this was not possible due to financial reasons and the timeframe of the follow-up project. Hänninen (2004) points out that in social storytelling settings narratives that are dramatic and coherent and that present the narrator in a favorable light are preferred, whereas problematic experiences that carry potential stigma are often held private and untold. In this study the interviewees shared extremely difficult and sensitive life events, such as divorce, domestic violence or serious illness of a family member and reinterpreted these experiences from the vantage point of the present. This refers to experiencing the interview situation as safe and the interviewer as trustworthy and easy to approach. Based on this, we find one long interview session with each participant to be sufficient for the purposes of this study.

Secondly, the data may be skewed by the characteristics of the sample. The participants were all women and the majority of them were no longer in a paid work role. Life stories of men with fibromyalgia – and of women who manage to remain at work– might bring new aspects into the discussion and should therefore be explored in the future. Thirdly, it is possible that the narratives are biased by memory distortions, especially when describing events that happened decades ago. In this study, memory bias was counteracted by the interview method where the original narrative was fulfilled and deepened by questions that emerged from the account. Moreover, we must bear in mind that in narrative research the focus is not on verification of events as facts, but rather on the interpretation of meaningful events (Atkinson, 2001; Bruner 2004, Bruner, 1991). Finally, taking a qualitative approach, we recognize that different interpretations of the data are possible and that both the interviewer and the interviewee have contributed to the nature and content of the data. Hence, the results presented here cannot be generalized as such; rather than that, they should be seen as particular points of view on fibromyalgia patients' life stories that evolved during this study.

The present study brought together the experiences of twenty middle-aged women with a long history of fibromyalgia. This study provides insights into how women with fibromyalgia interpret their life events and how they link them to their illness experiences. It is noteworthy that in all the life stories health, illness and functioning were predominantly reflected through the ability to or inability to work. This mirrors the importance of paid work role in Finnish women's lives, not only from an economic standpoint, but also as a definer of identity. This is in accordance with Crooks (2007), who pointed out that women with fibromyalgia often experience a loss of identity due to work-related disability, which changes their lifeworlds and social networks significantly.

Although all the life stories of the study are to be appreciated for their own merit, we were able to find similarities and differences in the storylines and to create three model narratives. Moreover, the counter-narrative presented in this study gives us the possibility to emphasize the fluctuating nature of fibromyalgia; recovery is possible! It also challenges us to see that categorization of life experiences can never be conclusive or consistent, but can be countered by different interpretations and by individual frames of discourse, as suggested by Bamberg (2004).

The narrative of 'mundane life' resembles the restitution narratives described by Arthur Frank (1995). In this narrative, normal life was temporarily disrupted by fibromyalgia, but continued later as expected. Frank condenses this: ”I was healthy, then I fell sick and now I am well again”. In the 'mundane life' narratives, fibromyalgia is accepted as a part of life, and it only disturbs life from time to time. The second model narrative was labeled with cumulative life events that gradually led to a situation where the persons' resources were no longer adequate for retaining wellbeing. The onset of fibromyalgia was perceived as a result of long-term distress and uncontrollable fatigue. Hatcher and House

(2003) suggest that not only traumatic life events but also daily dilemmas may be associated with the onset chronic widespread pain. They defined dilemmas as situations where a person is challenged to choose between equally undesirable alternatives. In our data, several such situations were described; e.g. whether to take care of one's elderly mother and ignore one's own fatigue or to rest and ignore the needs of others? Van Houdenhove, Neerinckx, Onghena, Lysens & Vertommen et al. (2001) point out that an overactive lifestyle and 'action-proneness' may lead to overburdening of the body by musculoskeletal overuse or sleep deprivation and that inability to set limits may lead to self-handicapping strategies, and thus predispose and perpetuate the symptoms in fibromyalgia. Similarly, the recurrent complaints of fatigue, worry and fear that were vividly described in the narratives of this study can be understood as emotional states where the whole body is tensed and where the life situation gives no possibilities to relax and to recover and which may thus lead to onset of widespread pain and other symptoms that are typical in fibromyalgia. Hence, this narrative study also contributes to the ongoing general discussion on the etiology, development and maintenance of fibromyalgia.

The 'broken life' narratives were characterized by traumatic experiences that had changed the course of life permanently. The onset of fibromyalgia was seen as an inevitable result of years of fatigue, worry and fear, in addition to physical or mental traumas caused by the unbearable life events. In many cases the events were 'silent secrets' that were not shared with health professionals, let alone with friends or colleagues. In many cultures – ours included– family violence and abuse are perceived as taboos. Although narrative study cannot show causalities or give prevalence of violence or other traumatic events among fibromyalgia patients, it has the power to highlight the suffering that lies beyond these experiences and to give voice to stories that have not been heard before. Thus, the present study accords with and expands the knowledge of the impact of traumatic life events reported in several quantitative studies on fibromyalgia. (Haviland et al., 2010; Kendall-Tackett, Marshall & Ness, 2003; Campbell, 2002; Anderberg et al., 2000.)

In conclusion, the present study gives insights into invisible symptoms and unheard experiences, which may help us to understand the individual suffering that is associated with fibromyalgia. The power of narratives lies not only in their ability to provide an experience of sameness with other patients with similar experiences or a similar illness, but also in their ability to reach for the meanings that people give to their illness and recovery. In health care and rehabilitation settings it is important to recognize fibromyalgia patients with a complex or traumatic life history, because they may suffer from more severe psychological symptoms and may therefore need a different therapeutic approach compared to those with a less burdening background. It is, however, equally important to emphasize that fibromyalgia patients must not be labeled as victims of violence or abuse. The model narratives and their counter-narrative presented in this study reflect the diversity of meanings ascribed to fibromyalgia, which in turn highlight the importance of storytelling in exploration of the possible causes and consequences of chronic illnesses.

References

Anderberg, U. M.,Marteinsdottir, I.,Theorell, T. & von Knorring, L. (2000). The impact of life events in female patients with fibromyalgia and in female healthy controls. *European Psychiatry*, 15, 295-301.

Arnold, L. M., Crofford, L. J., Mease, P. J., Burgess, S. M., Palmer, S. C., Abetz, L. et al. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counseling*, 73, 114-20.

Atkinson, R. (2001). The life story interview. In J. Gubrium & J. Holstein (Eds.), *Handbook of Interview Research: Context & Method* (pp. 121-119). Thousand Oaks: Sage.

Bailey, B. E.,Freedenfeld, R. N., Sanford Kiser, R. & Gatchel, R. J. (2003). Lifetime physical and sexual abuse in chronic pain patients: psychosocial correlates and treatment outcomes. *Disability and Rehabilitation*, 25, 331-342.

Bamberg, M. (2004). Considering counter narratives. In M. Bamberg & M. Andrews (eds.) Considering counter-narratives: narrating resisting, making sense. (pp.351-371). Amsterdam: John Benjamins B.V.

Bliddahl, H.& Danneskiold-Samsøe, B. (2008). Chronic widespread pain in the spectrum of rheumatological diseases. *Best Practice & Research in Clinincal Rheumatology*, 21, 391-402.

Branco, J.,Bannwarth, B.,Failde, I.,Carbonell, J.,Blotman, F.,Spaeth, M. et al. (2010). Prevalence of Fibromyalgia: A Survey in Five European Countries. *Seminars in Arthritis and Rheumatism,* 39, 448-453.

Bruner, J. (2004). Life as Narrative. *Social Research*, 71, 691-710.

Bruner, J. (1991). The Narrative Construction of Reality. *Critical Inquiry*, 18, 1-21.

Buskila, D. (2007). Genetics in Chronic Pain States. *Best Practice & Research Clinical Rheumatology* , 21, 535-554.

Campbell, C.& Cramb, G. (2008). 'Nobody likes a back bore' - exploring lay perspectives of chronic pain: revealing the hidden voices on nonservice users. *Scandinavian Journal of Caring Sciences*, 22, 383-390.

Campbell, J. C. (2002). Health consequences of intimat partner violence. *Lancet*, 359, 1331-1336.

Coyle, N. (2004). In their own words: Seven Advanced Cancer Patients Describe their Experieinces with Pain and the Use of Opioid Drugs. *Journal of Pain and Symptom Management*, 27, 300-309.

Crooks, V. A. (2007). Exploring the altered daily geographies and lifeworld of women living with fibromyalgia syndrome: A mixed-method approach. *Social Science and Medicine*, 64, 577-588.

Dadabhoy, D.,Crofford, L.,Spaeth, M.,Russel, IJ & Clauw, D. (2008). Evidence-based biomarkers for fibromyalgia syndrome. *Arthritis Reseach & Therapy*, 10, 211 (doi:10.1186/ar2443).

Frank, A. (1995). *The wounded storyteller.* Chigago: University of Chigago Press.

Gupta, A. & Silman, A. J. (2004). Psycological stress and fibromyalgia: a review of the evidence suggesting a neuroendocrine link. *Arthritis Research & Therapy*, 6, 98-106.

Hatcher, S.& House, A. (2003). Life events, difficulties and dilemmas in the onset of chronic fatigue syndrome: a case- control study. *Psychological Medicine*, 33, 1185-1192.

Haviland, M. G.,Morton, K. R.,Oda, K., & Fraser, G. E. (2010). Traumatic experiences, major life stressors, and self-reporting a physician-given fibromyalgia diagnosis. *Psychiatry Research*, 177, 335-341.

Hydén, L.-C. (1997). Illness and Narrative. *Sociology of Health and Illness*, 19, 48-69.

Hyden, M. (2005). ‘I Must Have Been an Idiot to Let it Go On’: Agency and Positioning in Battered Women’s Leaving. *Feminism & Psychology*, 15, 169-188.

Hyvärinen, M. (2008). Analyzing Narratives and Story-telling. In P. Alasuutari, L. Bickman L& J.Brannen (Eds.), *The SAGE Handbook of Social Research Methods* (pp. 447- 460). London: Sage.

Hänninen, V. (2004). A model of narrative circulation. *Narrative Inquiry*, 14, 69-85.

Jones, G. T.,Power, C.& Macfarlane, G. J. (2009). Adverse events in childhood and chronic widepread pain in adult life: results from the 1958 British Birth Cohort Study. *Pain*, 143, 92-96.

Kendall-Tackett, K.,Marshall, R.& Ness, K. (2003). Chronic Pain Syndromes and Violence Against Women. *Women and Therapy*, 26, 45-56.

Kukkurainen ML. (2006). Fibromyalgiaa sairastavien koherenssintunne, sosiaalinen tuki ja elämänlaatu [Fibromyalgia patients' sense of coherence, social support and quality of life]. Dissertation. Oulu: University of Oulu.

Labov, W.& Waletsky, J. (2003). Narrative Analysis: Oral Versions of Personal Experience [reprint from 1967]. In C. Bratt Paulston & G. Tucker (Eds.), *Sociolinguistics: the Essential Readings* (pp. 74-104). Oxford: Blackwell.

Lampe, A.,Doering, S.,Rumpold, G.,Sölder, E.,Krismer, M.,Kantner-Rumplmair, W. et al. (2003). Chronic pain syndromes and their relation to childhood abuse and stressful life events. *Journal of Psychosomatic Research*, 54, 361-367.

Lonardi, C. (2007). The passing dilemma in socially invisible diseases: narratives on chronic headache. *Social Science and Medicine* , 65, 1619-1629.

McBeth J, Silman A.J., Gupta A., Chiu Y.H. Ray D., Morris R. et al. (2007). Moderation of Psychological Risk Factors Through Dysfunction of the Hypothalamic-Pituitary-Adrenal Axis in the Onset of Chronic Widespread Musculoskeletal Pain. *Arthritis & Rheumatism*, 56, 360-377.

McGowan, L.,Luker, K.,Creed, F.& Chew-Graham, C. A. (2007). 'How do you explain a pain that can't be seen': the narratives of women with chronic pelvic pain and their disengagement with the disagnostic cycle. *British Journal of Health Psychology*, 12, 261-274.

Nicholl, B. I.,Macfarlane, G. J.,Davies, K. A.,Morriss, R., Dickens, C. & McBeth, J. (2009). Premorbid psychosocial factors are associated with poor health-related quality of life in subjects with new onset of chronic widepread pain- Result from the EPIFUND study. *Pain* , 141, 119-126.

Polkinghorne, D. E. (1996). Narrative Knowing and the Study of Lives. In J. E. Birren (Ed), *Aging and biography: explorations in adult development* (pp. 77-99). New York: Springer.

Randall, W. L., Prior, S. M.& Skarborn, M. (2006). How listeners shape what tellers tell. Patterns of interaction in life story interviews and their impact on reminiscencse by elderly interviewees. *Journal of Aging Studies*, 20, 381-396.

Richardson, J. C., Ong, B. N. & Sim, J. (2006). Is chronic widespread pain biographically disruptive? *Social Science and Medicine*, 63, 1573-1585.

Riessman, C. (2001). Analysis of personal narratives. In J.Gubrium & J. Holstein (Eds.), *Handbook of Interview Research: Context & Methods* (pp. 695-707). Thousand Oaks: Sage.

Riessman, C. & Speedy, J. (2007). Narrative inquiry in the psychotherapy professions. In D. Clandinin, *Handbook of Narrative Inquiry* (pp. 426-456). London: Sage.

Rosenthal, G. (2003). The healing effects of storytelling: on the conditions of curative storytelling in the context of research and counselling. *Qualitative Inquiry*, 9, 915-933.

Sallinen, M.,Kukkurainen, M. L.,Peltokallio, L. & Mikkelsson, M. (2010). Women's Narratives on Experiences of Work Ability and Functioning in Fibromyalgia. *Musculoskeletal Care* , 8, 18-26.

Sallinen, M.,Kukkurainen, M. L.,Peltokallio, L.& Mikkelsson, M. (2011). 'I am tired of being tired' - Fatigue as Experienced by Women with Fibromyalgia. *Advances in physiotherapy* (in press). doi:10.319/14038196.2010.546880

Van Houdenhove, B., Neerinckx, E., Onghena, P., Lysens, R. & Vertommen, H. (2001). Premorbid "overactive" lifestyle in chronic fatigue syndrome and fibromyalgia. An etiological factor or proof of good citizenship? *Journal of Psychosomatic Research*, 51, 571-576.

van Ittersum, M. W., van Wilgen, C. P., Hilberdink, W. K.,Groothoff, J. W.& van der Schans, C. P. (2009). Illness Perceptions in Patients with Fibromyalgia. *Patient Education and Counseling*, 74, 53-60.

van Wilgen, C., van Ittersum, M. W., Kaptein, A. A. & van Wijhe, M. (2008). Illness Perception in Patients with Fibromyalgia and Their Relation to Quality of Life and Catastrophizing. *Arthritis & Rheumatism*, 59, 3618-3626.

Wengraf, T. (2001). *Qualitative research interviewing: biographic narrative and semistructured methods.* London: Sage.

Wolfe, F., Clauw, D., Fitzcharles, M.-A., Goldenberg, D., Katz, R., Mease, P. et al. (2010). The American College of Rheumatology Preliminary Diagnostic Criteria for Fibrolmyalgia Syndrome and Measurement of Symptom Severity. *Arthritis Care& Research*, 62, 600-610.

Vroman, K., Warner, R. & Chamberlain, K. (2009). Now let me tell you in my own words: narratives of acute and chronic low back pain. *Disability and Rehabilitation*, 31, 976-987.

Yunus, M. (2007). Fibromyalgia and overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes. *Seminars in Arthiris & Rheumatism*, 36, 339-356.

Åsbring, P. (2001). Chronic illness- a disruption in life: identity transformation among women with chronic fatigue syndrome and fibromyalgia. *Issues and innovations in nursing practice*, 34, 312-319.

Figure 1. The stepwise process of analysis

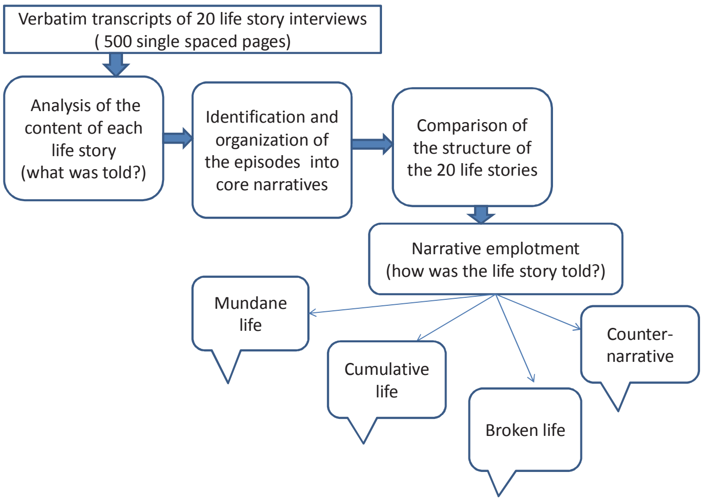


Table 1. Descriptive summary of the main findings

	Mundane life	Cumulative life	Broken life	Counter-narrative
Life before illness	normal, safe, expected	cumulating daily hassles and worries	traumatic events	comparable to other participants
Perceived cause of the symptoms	overloading, sleeping problems	fatigue, distress	tension, fear, exhaustion, physical and mental traumas	injury, overload, tension
Metaphora of rehabilitation course	source of information and support	time of one's own	escape	
Life after rehabilitation	return to work	fragmented work history	depression, increasing disability, exhaustion	full recovery
Perceived current functioning	maintaining paid work role with the help of adaptations at work and with social support	poor work ability/ disability	loss of control, lost work ability and poor functioning in general	healthy

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

1 Kirjonen, Juhani, On the description of a human movement and its psychophysical correlates under psychomotor loads. 48 p. 1971.

2 Kirjonen, Juhani ja Rusko, Heikki, Liikkeen kinemaattisista ominaispiirteistä, niiden psykofyysisistä selitysyhteyksistä ja näiden muutoksista psykomotorisen kuormituksen ja kestävyysharjoittelun vaikutuksesta. - On the kinematic characteristics and psychophysical correlates of a human movement and their changes during psychomotor loading and endurace conditioning. 156 p. 1971.

3 Sarviharju, Pekka J., Effects of psycho-physical loading and progressive endurance conditioning on selected biochemical correlates of adaptive responses in man. 95 p. 1973.

4 Kiviaho, Pekka, Sport organizations and the structure of society. 54 p. 1973.

5 Komi, Paavo V., Nelson, Richard C. and Pulli, Matti, Biomechanics of skijumping. 53 p. 1974.

6 Meteli, Työolot, terveys ja liikuntakäyttäytyminen metallitehtaissa. Kartoittavan kyselyn aineistot ja toteuttaminen. 178 p. 1974.

7 Tiainen, Jorma M., Increasing physical education students' creative thinking. 53 p. 1976.

8 Rusko, Heikki, Physical performance characteristics in Finnish athletes. 40 p. 1976.

9 Kiiskinen, Anja, Adaptation of connective tissues to physical training in young mice. 43 p. 1976.

10 Vuolle, Pauli, Urheilu elämänsisältönä. Menestyneiden urheilijoiden elämänura kilpailuvuosina - Top sport as content of life. 227 p. 1977.

11 Suominen, Harri, Effects of physical training in middle-aged and elderly people with special regard to skeletal muscle, connective tissue, and functional aging. 40 p. 1978.

12 Viitasalo, Jukka, Neuromuscular performance in voluntary and reflex contraction with special reference to muscle structure and fatigue. 59 p. 1980.

13 Luhtanen, Pekka, On the mechanics of human movement with special reference to walking, running and jumping. 58 p. 1980.

14 Laakso, Lauri, Lapsuuden ja nuoruuden kasvuympäristö aikuisiän liikuntaharrastusten selittäjänä: retrospektiivinen tutkimus. - Socialization environment in childhood and youth as determinant of adult-age sport involvement: a retrospective study. 295 p. 1981.

15 Bosco, Carmelo, Stretch-schortening cycle inskeletal muscle function with special reference to elastic energy and potentiation of myoelectrical activity. 64 p. 1982.

16 Olin, Kalevi, Päätöksentekijöiden viiteryhmät kaupunkien liikuntapolitiikassa. - Reference groups of decision-makers in the sport politics of cities. 155 p. 1982.

17 Kannas, Lasse, Tupakointia koskeva terveyskasvatus peruskoulussa. - Health education on smoking in the Finnish comprehensive school. 251 p. 1983.

18 Contribution of sociology to the study of sport. Festschrift Book in Honour of Professor Kalevi Heinilä. Ed. by Olin, K. 243 p. 1984.

19 Alén, Markku, Effects of self-administered, high-dose testosterone and anabolic steroids on serum hormones, lipids, enzymes and on spermatogenesis in power athletes. 75 p. 1985.

20 Häkkinen, Keijo, Training and detraining adaptations in electromyographic, muscle fibre and force production characteristics of human leg extensor muscles with special reference to prolonged heavy resistance and explosive type strength training. 106 p. 1986.

21 Lahtinen, Ulla, Begåvningshandikappad ungdom i utveckling. En uppföljningstudie av funktionsförmåga och fysisk aktivitet hos begåvningshandikappade ungdomar i olika livsmiljöer. 300 p. 1986.

22 Silvennoinen, Martti, Koululainen liikunnanharrastajana: liikuntaharrastusten ja liikuntamotiivien sekä näiden yhteyksien muuttuminen iän mukana peruskoululaisilla ja lukiolaisilla. - Schoolchildren and physically active interests: The changes in interests in and motives for physical exercise related to age in Finnish comprehensive and upper secondary schools. 226 p. 1987.

23 Pohjolainen, Pertti, Toimintakykyisyys, terveydentila ja elämäntyyli 71-75-vuotiailla miehillä. - Functional capacity, health status and life-style among 71-75 year-old men. 249 p. Summary 13 p. 1987.

24 Mero, Antti, Electromyographic acticity, force and anaerobic energy production in sprint running; with special reference to different constant speeds ranging from submaximal to supramaximal. 112 p. Tiivistelmä 5 p. 1987.

25 Parkatti, Terttu, Self-rated and clinically measured functional capacity among women and men in two age groups in metal industry. 131 p. Tiivistelmä 2 p. 1990.

26 Holopainen, Sinikka, Koululaisten liikuntataidot. - The motor skills of schoolboys and girls. 217 p. Summary 6 p. 1990.

27 Numminen, Pirkko, The role of imagery in physical education. 131 p. Tiivistelmä 10 p. 1991.

28 Talvitie, Ulla, Aktiivisuuden ja omatoimivuuden kehittäminen fysioterapian tavoitteena. Kehittävän työntutkimuksen sovellus lääkintävoimistelijan työhön. - The development of activity and self-motivation as the aim of physiotherapy. The application of developmental work research in physiotherapy. 212 p. Summary 8 p. 1991.

29 Kahila, Sinikka, Opetusmenetelmän merkitys prososiaalisessa oppimisessa - auttamiskäyttäytymisen edistäminen

yhteistyöskentelyn avulla koululiikunnassa. - The role of teaching method in prosocial learning - developing helping behavior by means of the cooperative teaching method in physical education. 132 p. Summary 2 p. 1993.

30 Liimatainen-Lamberg, Anna-Ester, Changes in student smoking habits at the vocational institutions and senior secondary schools and health education. 195 p. Yhteenveto 5 p. 1993.

31 Keskinen, Kari Lasse, Stroking characteristics of front crawl swimming. 77 p. Yhteenveto 2 p. 1993.

32 Rantanen, Taina, Maximal isometric strength in older adults. Cross-national comparisons, background factors and association with mobility. 87 p. Yhteenveto 4 p. 1994.

33 Lusa, Sirpa, Job demands and assessment of the physical work capacity of fire fighters. 91 p. Yhteenveto 4 p. 1994.

34 Cheng, Sulin, Bone mineral density and quality in older people. A study in relation to exercise and fracture occurrence, and the assessment of mechanical properties. 81 p. Tiivistelmä 1 p. 1994.

35 Koski, Pasi, Liikuntaseura toimintaympäristössään. - Sports club in its organizational environment. 220 p. Summary 6 p. 1994.

36 Juppi, Joel, Suomen julkinen liikuntapolitiikka valtionhallinnon näkökulmasta vuosina 1917-1994. - Public sport policy in Finland from the viewpoint of state administration in 1917-1994. 358 p. Summary 7 p. 1995.

37 Kyröläinen, Heikki, Neuromuscular performance among power- and endurance-trained athletes. 82 p. Tiivistelmä 3 p. 1995.

38 Nyandindi, Ursuline S., Evaluation of a school oral health education programme in Tanzania: An ecological perspective. 88 p. Tiivistelmä 2 p. 1995.

39 Heikinaro-Johansson, Pilvikki, Including students with special needs in physical education. 81 p. Yhteenveto 4 p. 1995.

40 Sarlin, Eeva-Liisa, Minäkokemuksen merkitys liikuntamotivaatiotekijänä. - The significance of self perception in the motivational orientation of physical education. 157 p. Summary 4 p. 1995.

41 Lintunen, Taru, Self-perceptions, fitness, and exercise in early adolescence: a four-year follow-up study. 87 p. Yhteenveto 5 p.1995.

42 Sipilä, Sarianna, Physical training and skeletal muscle in elderly women. A study of muscle mass, composition, fiber characteristics and isometric strength. 62 p. Tiivistelmä 3 p. 1996.

43 Ilmanen, Kalervo, Kunnat liikkeellä. Kunnallinen liikuntahallinto suomalaisen yhteiskunnan muutoksessa 1919-1994. - Municipalities in motion. Municipal sport administration in the changing Finnish society 1919-1994. 285 p. Summary 3 p. 1996.

44 Nummela, Ari, A new laboratory test method for estimating anaerobic performance characteristics with special reference to sprint running. 80 p. Yhteenveto 4 p. 1996.

45 Varstala, Väinö, Opettajan toiminta ja oppilaiden liikunta-aktiivisuus koulun liikuntatunnilla. - Teacher behaviour and students' motor engagement time in school physical education classes. 138 p. Summary 4 p. 1996.

46 Poskiparta, Marita, Terveysneuvonta, oppimaan oppimista. Videotallenteet hoitajien terveysneuvonnan ilmentäjinä ja vuoro-vaikutustaitojen kehittämismenetelmänä. - Health counselling, learning to learn. Video-tapes expressing and developing nurses´ communication skills. 159 p. Summary 6 p. 1997.

47 Simonen, Riitta, Determinants of adult psychomotor speed. A study of monozygotic twins. - Psykomotorisen nopeuden determinantit identtisillä kaksosilla. 49 p. Yhteenveto 2 p. 1997.

48 Nevala-Puranen, Nina, Physical work and ergonomics in dairy farming. Effects of occupationally oriented medical rehabilitaton and environmental measures. 80 p. (132 p.) 1997.

49 Heinonen, Ari, Exercise as an Osteogenic Stimulus. 69 p. (160 p.) Tiivistelmä 1 p. 1997.

50 Vuolle, Pauli (Ed.) Sport in social context by Kalevi Heinilä. Commemorative book in Honour of Professor Kalevi Heinilä. 200 p. 1997.

51 Tuomi, Jouni, Suomalainen hoitotiedekeskustelu. - The genesis of nursing and caring science in Finland. 218 p. Summary 7 p. 1997.

52 Tolvanen, Kaija, Terveyttä edistävän organisaation kehittäminen oppivaksi organisaatioksi. Kehitysnäytökset ja kehittämistehtävät terveyskeskuksen muutoksen virittäjänä. - Application of a learning organisation model to improve services in a community health centre. Development examples and development tasks are the key to converting a health care. 197 p. Summary 3 p. 1998.

53 Oksa, Juha, Cooling and neuromuscular performance in man. 61 p. (121 p.) Yhteenveto 2 p. 1998.

54 Gibbons, Laura, Back function testing and paraspinal muscle magnetic resonance image parameters: their associations and determinants. A study on male, monozygotic twins. 67 p (128 p.) Yhteenveto 1p. 1998.

55 Nieminen, Pipsa, Four dances subcultures. A study of non-professional dancers´ socialization, participation motives, attitudes and stereotypes. - Neljä tanssin alakulttuuria. Tutkimus tanssinharrastajien tanssiin sosiaalistumisesta, osallistumismotiiveista, asenteista ja stereotypioista. 165 p. Yhteenveto 4 p. 1998.

56 Laukkanen, Pia, Iäkkäiden henkilöiden selviytyminen päivittäisistä toiminnoista. - Carrying out the activities of daily living among elderly people. 130 p. (189 p.). Summary 3 p. 1998.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

57 Avela, Janne, Stretch-reflex adaptation in man. Interaction between load, fatigue and muscle stiffness. 87 p. Yhteenveto 3 p. 1998.

58 Suomi, Kimmo, Liikunnan yhteissuunnittelumetodi. Metodin toimivuuden arviointi Jyväskylän Huhtasuon lähiössä. - Collaborative planning method of sports culture. Evaluation of the method in the Huhtasuo suburb of the city of Jyväskylä. 190 p. Summary 8 p. 1998.

59 Pötsönen, Riikka, Naiseksi, mieheksi, tietoiseksi. Koululaisten seksuaalinen kokeneisuus, HIV/AIDS-tiedot, -asenteet ja tiedonlähteet. - Growing as a woman, growing as a man, growing as a conscious citizen. 93 p. (171 p.). Summary 3 p. 1998.

60 Häkkinen, Arja, Resistance training in patients with early inflammatory rheumatic diseases. Special reference to neuromuscular function, bone mineral density and disease activity. - Dynaamisen voimaharjoittelun vaikutukset nivelreumaa sairastavien potilaiden lihasvoimaan, luutiheyteen ja taudin aktiivisuuteen. 62 p. (119 p.) Yhteenveto 1 p. 1999.

61 Tynjälä, Jorma, Sleep habits, perceived sleep quality and tiredness among adolescents. A health behavioural approach. - Nuorten nukkumistottumukset, koettu unen laatu ja väsyneisyys. 104 p. (167 p.) Yhteenveto 3 p. 1999.

62 Pönkkö, Anneli, Vanhemmat ja lastentarhanopettajat päiväkotilasten minäkäsityksen tukena. - Parents´ and teachers´ role in self-perception of children in kindergartens. 138 p. Summary 4 p. 1999.

63 Paavolainen, Leena, Neuromuscular characteristics and muscle power as determinants of running performance in endurance athletes with special reference to explosive-strength training. - Hermolihasjärjestelmän toimintakapasiteetti kestävyyssuorituskykyä rajoittavana tekijänä. 88 p. (138 p.) Yhteenveto 4 p. 1999.

64 Virtanen, Paula, Effects of physical activity and experimental diabetes on carbonic anhydrace III and markers of collagen synthesis in skeletal muscle and serum. 77 p. (123 p.) Yhteenveto 2 p. 1999.

65 Kepler, Kaili, Nuorten koettu terveys, terveyskäyttäytyminen ja sosiaalistumisympäristö Virossa. - Adolescents' perceived health, health behaviour and socialisation enviroment in Estonia. - Eesti noorte tervis, tervisekäitumine ja sotsiaalne keskkond. 203 p. Summary 4p. Kokkuvõte 4 p. 1999.

66 Suni, Jaana, Health-related fitness test battery for middle-aged adults with emphasis on musculoskeletal and motor tests. 96 p. (165 p.) Yhteenveto 2 p. 2000.

67 Syrjä, Pasi, Performance-related emotions in highly skilled soccer players. A longitudinal study based on the IZOF model. 158 p. Summary 3 p. 2000.

68 Välimaa, Raili, Nuorten koettu terveys kyselyaineistojen ja ryhmähaastattelujen valossa. - Adolescents' perceived health based on surveys and focus group discussions. 208 p. Summary 4 p. 2000.

69 Kettunen, Jyrki, Physical loading and later lower-limb function and findings . A study among male former elite athletes. - Fyysisen kuormituksen yhteydet alaraajojen toimintaan ja löydöksiin entisillä huippu-urhelijamiehil-lä. 68 p. (108 p.) Yhteenveto 2 p. 2000.

70 Horita, Tomoki, Stiffness regulation during stretch-shortening cycle exercise. 82 p. (170 p.) 2000.

71 Helin, Satu, Iäkkäiden henkilöiden toimintakyvyn heikkeneminen ja sen kompensaatioprosessi. - Functional decline and the process of compensation in elderly people. 226 p. Summary 10 p. 2000.

72 Kuukkanen, Tiina, Therapeutic exercise programs and subjects with low back pain. A controlled study of changes in function, activity and participation. 92 p. (154 p.) Tiivistelmä 2 p. 2000.

73 Virmavirta, Mikko, Limiting factors in ski jumping take-off. 64 p. (124 p.) Yhteenveto 2 p. 2000.

74 Peltokallio, Liisa, Nyt olisi pysähtymisen paikka. Fysioterapian opettajien työhön liittyviä kokemuksia terveysalan ammatillisessa koulutuksessa. - Now it's time to stop. Physiotherapy teachers' work experiences in vocational health care education. 162 p. Summary 5 p. 2001.

75 Kettunen, Tarja, Neuvontakeskustelu. Tutkimus potilaan osallistumisesta ja sen tukemisesta sairaalan terveysneuvonnassa. - Health counseling conversation. A study of patient participation and its support by nurses during hospital counseling. 123 p. (222 p.) Summary 6 p. 2001.

76 Pullinen, Teemu, Sympathoadrenal response to resistance exercise in men, women and pubescent boys. With special reference to interaction with other hormones and neuromuscular performance. 76 p. (141 p.) Yhteenveto 2 p. 2001.

77 Blomqvist, Minna, Game understanding and game performance in badminton. Development and validation of assessment instruments and their application to games teaching and coaching. 83 p. Yhteenveto 5 p. 2001.

78 Finni, Taija, Muscle mechanics during human movement revealed by in vivo measurements of tendon force and muscle length. 83 p. (161 p.) Yhteenveto 3 p. 2001.

79 Karimäki, Ari, Sosiaalisten vaikutusten arviointi liikuntarakentamisessa. Esimerkkinä Äänekosken uimahalli. - Social impact assessment method in sports planning. - The case of Äänekoski leisure pool. 194 p. 2001.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

80 Peltonen, Juha, Effects of oxygen fraction in inspired air on cardiorespiratory responses and exercise performance. 86 p. (126 p.) Yhteenveto 2 p. 2002.

81 Heinilä, Liisa, Analysis of interaction processes in physical education. Development of an observation instrument, its application to teacher training and program evaluation. 406 p. Yhteenveto 11 p. 2002.

82 Linnamo, Vesa, Motor unit activation and force production during eccentric, concentric and isometric actions. - Motoristen yksiköiden aktivointi ja lihasten voimantuotto eksentrisessä, konsentrisessa ja isometrisessä lihastyössä. 77 p. (150 p.) Yhteenveto 2 p. 2002.

83 Perttunen, Jarmo, Foot loading in normal and pathological walking. 86 p. (213 p.) Yhteenveto 2 p. 2002.

84 Leinonen, Raija, Self-rated health in old age. A follow-up study of changes and determinants. 65 p. (122 p.) Yhteenveto 2 p. 2002.

85 Gretschel, Anu, Kunta nuorten osallisuusympäristönä. Nuorten ryhmän ja kunnan vuorovaikutussuhteen tarkastelu kolmen liikuntarakentamisprojektin laadunarvioinnin keinoin. - The municipality as an involvement environment - an examination of the interactive relationship between youth groups and municipalities through the quality assessment of three sports facilities construction projects. 236 p. Summary 11 p. 2002.

86 Pöyhönen, Tapani, Neuromuscular function during knee exercises in water. With special reference to hydrodynamics and therapy. 77 p. (124 p.) Yhteenveto 2 p. 2002.

87 Hirvensalo, Mirja, Liikuntaharrastus iäkkäänä. Yhteys kuolleisuuteen ja avuntarpeeseen sekä terveydenhuolto liikunnan edistäjänä. - Physical activity in old age - significance for public health and promotion strategies. 106 p. (196 p.) Summary 4 p. 2002.

88 Kontulainen, Saija, Training, detraining and bone - Effect of exercise on bone mass and structure with special reference to maintenance of exercise induced bone gain. 70 p. (117 p.) Yhteenveto 2 p. 2002.

89 Pitkänen, Hannu, Amino acid metabolism in athletes and non-athletes. - With Special reference to amino acid concentrations and protein balance in exercise, training and aging. 78 p. (167 p.) Yhteenveto 3 p. 2002.

90 Liimatainen, Leena, Kokemuksellisen oppimisen kautta kohti terveyden edistämisen asiantuntijuutta. Hoitotyön ammattikorkeakouluopiskelijoiden terveyden edistämisen oppiminen hoitotyön harjoittelussa.- Towards health promotion expertise through experiential learning. Student nurses' health promotion learning during clinical practice. 93 p. (164 p.) Summary 4 p. 2002.

91 Ståhl, Timo, Liikunnan toimintapolitiikan arviointia terveyden edistämisen kontekstissa. Sosiaalisen tuen, fyysisen ympäristön ja poliittisen ympäristön yhteys liikunta-aktiivisuuteen. - Evaluation of the Finnish sport policy in the context of health promotion. Relationships between social support, physical environment, policy environment and physical activity 102 p. (152 p.) Summary 3 p. 2003.

92 Ogiso, Kazuyuki, Stretch Reflex Modulation during Exercise and Fatigue. 88 p. (170 p.) Yhteenveto 1 p. 2003.

93 Rauhasalo, Anneli, Hoitoaika lyhenee – koti kutsuu. Lyhythoitoinen kirurginen toiminta vanhusten itsensä kokemana. - Care-time shortens – home beckons. Short term surgical procedures as experienced by elderly patients. 194 p. Summary 12 p. 2003.

94 Palomäki, Sirkka-Liisa, Suhde vanhenemiseen. Iäkkäät naiset elämänsä kertojina ja rakentajina. - Relation to aging. Elderly women as narrators and constructors of their lives. 143 p. Summary 6 p. 2004.

95 Salmikangas, Anna-Katriina, Nakertamisesta hanketoimintaan. Tapaustutkimus Nakertaja-Hetteenmäen asuinalueen kehittämistoiminnasta ja liikunnan osuudesta yhteissuunnittelussa. - From togetherness to project activity. A case study on the development of a neighbourhood in Kainuu and the role of physical activity in joint planning. 269 p. Summary 8 p. 2004.

96 Ylönen, Maarit E., Sanaton dialogi. Tanssi ruumiillisena tietona. - Dialogue without words. Dance as bodily knowledge. 45 p. (135 p.) Summary 5 p. 2004.

97 Tummavuori, Margareetta, Long-term effects of physical training on cardiac function and structure in adolescent cross-country skiers. A 6.5-year longitudinal echocardiographic study. 151 p. Summary 1 p. 2004.

98 Sirola, Kirsi, Porilaisten yhdeksäsluokkalaisten ja kasvattajien käsityksiä nuorten alkoholinkäytöstä ja alkoholinkäytön ehkäisystä. - Views of ninth graders, educators and parents in Pori, Finland on adolescent alcohol use and on preventing alcohol use. 189 p. Summary 3 p. 2004.

99 Lampinen, Päivi, Fyysinen aktiivisuus, harrastustoiminta ja liikkumiskyky iäkkäiden ihmisten psyykkisen hyvinvoinnin ennustajina. 65–84-vuotiaiden jyväskyläläisten 8-vuotisseuruu-tutkimus. - Activity and mobility as associates and predictors of mental well-being among older adults. 94 p. (165 p.) Summary 2 p. 2004.

100 Ranta, Sari, Vanhenemismuutosten eteneminen. 75-vuotiaiden henkilöiden antropometristen ominaisuuksien, fyysisen toimintakyvyn ja kognitiivisen kyvykkyyden muutokset viiden ja kymmenen vuoden seuranta-aikana. - The progress of aging

processes. A 5- and 10-year follow-up study of the changes in anthropometrical characteristics and physical and cognitive capacities among 75-year-old persons. 186 p. Summary 2 p. 2004.

101 Sihvonen, Sanna, Postural balance and aging. Cross-sectional comparative studies and a balance training intervention. - Ikääntyminen ja tasapaino. Eri ikäisten tasapaino ja tasapainoharjoittelun vaikuttavuus ikääntyneillä palvelukodissa asuvilla naisilla. 65 p. (106 p.) Yhteenveto 2 p. 2004.

102 Rissanen, Aaro, Back muscles and intensive rehabilitation of patients with chronic low back pain. Effects on back muscle structure and function and patient disability. - Selkälihakset ja pitkäaikaista selkäkipua sairastavien potilaiden intensiivinen kuntoutus. Vaikutukset selkälihasten rakenteeseen ja toimintaan sekä potilaiden vajaakuntoisuuteen. 90 p. (124 p.) Yhteenveto 2 p. 2004.

103 Kallinen, Mauri, Cardiovascular benefits and potential hazards of physical exercise in elderly people. - Liikunnan hyödylliset ja mahdolliset haitalliset vaikutukset ikääntyneiden verenkiertoelimistöön. 97 p. (135 p). Yhteenveto 2 p. 2004.

104 Sääkslahti, Arja, Liikuntaintervention vaikutus 3–7-vuotiaiden lasten fyysiseen aktiivisuuteen ja motorisiin taitoihin sekä fyysisen aktiivisuuden yhteys sydän- ja verisuonitautien riskitekijöihin. - Effects of physical activity Intervention on physical activity and motor skills and relationships between physical activity and coronary heart disease risk factors in 3–7-year-old children. 153 p. Summary 3 p. 2005.

105 Hämäläinen, Piia, Oral health status as a predictor of changes in general health among elderly people. 76 p. (120 p.) Summary 2 p. 2005.

106 Liinamo, Arja, Suomalaisnuorten seksuaalikasvatus ja seksuaaliterveystiedot oppilaan ja koulun näkökulmasta. Arviointia terveyden edistämisen viitekehyksessä. - Sexual education and sexual health knowledge among Finnish adolescents at pupil and school level. Evaluation from the point of view of health promotion. 111 p. (176 p.) Summary 5 p. 2005.

107 Ishikawa, Masaki, In vivo muscle mechanics during human locomotion. Fascicle-tendinous tissue interaction during stretch-shortening cycle exercises. - Venytysrefleksin muutokset liikkeessä ja väsymyksessä. 89 p. (228 p.) Yhteenveto 1 p. 2005.

108 Kärki, Anne, Physiotherapy for the functioning of breast cancer patients. Studies of the effectiveness of physiotherapy methods and exercise, of the content and timing of post-operative education and of the experienced functioning and disability . - Rintasyöpäleikattujen toimintakyky ja siihen vaikuttaminen fysioterapiassa ja harjoittelussa. 70 p. (138 p.) Yhteenveto 3 p. 2005.

109 Rajaniemi, Vesa, Liikuntapaikkarakentaminen ja maankäytön suunnittelu. Tutkimus eri väestöryhmät tasapuolisesti huomioon ottavasta liikuntapaikkasuunnittelusta ja sen kytkemisestä maankäyttö- ja rakennuslain mukaiseen kaavoitukseen. - Sports area construction and land use planning – Study of sports area planning that considers all the population groups even-handedly and integrates sports area planning with land use planning under the land use and building act.
171 p. Summary 6 p. 2005.

110 Wang, Qingju, Bone growth in pubertal girls. Cross-sectional and lingitudinal investigation of the association of sex hormones, physical activity, body composition and muscle strength with bone mass and geometry. 75 p. (117 p.) Tiivistelmä 1 p. 2005.

111 Ropponen, Annina, The role of heredity, other constitutional structural and behavioral factors in back function tests.- Perimä, muut synnynnäiset rakenteelliset tekijät ja käyttäytymistekijät selän toimintakykytesteissä. 78 p. (125 p.) Tiivistelmä 1 p. 2006.

112 Arkela-Kautiainen, Marja, Functioning and quality of life as perspectives of health in patients with juvenile idiopathic arthritis in early adulthood. Measurement and long-term outcome. - Toimintakyky ja elämänlaatu terveyden näkökulmina lastenreumaa sairastaneilla nuorilla aikuisilla. Mittaaminen ja pitkäaikaistulokset. 95 p. (134 p.) Tiivistelmä 2 p. 2006.

113 Rautio, Nina, Seuruu- ja vertailututkimus sosioekonomisen aseman yhteydestä toimintakykyyn iäkkäillä henkilöillä. - A follow-up and cross-country comparison study on socio-economic position and its relationship to functional capacity in elderly people. 114 p. (187 p.) Summary 3 p. 2006.

114 Tiikkainen, Pirjo, Vanhuusiän yksinäisyys. Seuruutukimus emotionaalista ja sosiaalista yksinäisyyttä määrittävistä tekijöistä. - Loneliness in old age – a follow-up study of determinants of emotional and social loneliness. 76 p. (128 p.) Summary 2 p. 2006.

115 Ahtiainen, Juha, Neuromuscular, hormonal and molecular responses to heavy resistance training in strength trained men; with special reference to various resistance exercise protocols, serum hormones and gene expression of androgen receptor and insulin-like growth factor-I. - Neuromuskulaariset, hormonaaliset ja molekulaariset vasteet voimaharjoittelussa voimaurheilijoilla. 119 p. (204 p.) Yhteenveto 2 p. 2006.

116 Pajala, Satu, Postural balance and susceptibility to falls in older women. Genetic and environmental influences in single and dual task situations. - Iäkkäiden naisten tasapainokyky yksinkertaisissa sekä huomion jakamista vaativissa tilanteissa ja kaatumisriski-perimän merkitys yksilöiden välisten erojen selittäjinä. 78 p. (120 p.) Yhteenveto 3 p. 2006.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

117 Tiainen, Kristina, Genetics of skeletal muscle characteristics and maximal walking speed among older female twins. - Lihasvoiman ja kävelynopeuden periytyvyys iäkkäillä naiskaksosilla. 77 p. (123 p.) Yhteenveto 2 p. 2006.

118 Sjögren, Tuulikki, Effectiveness of a workplace physical exercise intervention on the functioning, work ability, and subjective well-being of office workers – a cluster randomised controlled cross-over trial with one-year follow-up. - Työpaikalla tapahtuvan fyysisen harjoitteluintervention vaikuttavuus toimistotyöntekijöiden toimintakykyyn, työkykyyn ja yleiseen subjektiiviseen elämänlaatuun – ryhmätasolla satunnaistettu vaihtovuorokoe ja vuoden seuranta. 100 p. (139 p.) Tiivistelmä 3 p. 2006.

119 Lyyra, Tiina-Mari, Predictors of mortality in old age. Contribution of self-rated health, physical functions, life satisfaction and social support on survival among older people. - Kuolleisuuden ennustetekijät iäkkäässä väestössä. Itsearvioidun terveyden, fyysisten toimintojen, elämään tyytyväisyyden ja sosiaalisen tuen yhteys iäkkäiden ihmisten eloonjäämiseen. 72 p. (106 p.) Tiivistelmä 2 p. 2006.

120 Soini, Markus, Motivaatioilmaston yhteys yhdeksäsluokkalaisten fyysiseen aktiivisuuteen ja viihtymiseen koulun liikuntatunneilla. - The relationship of motivational climate to physical activity intensity and enjoyment within ninth grade pupils in school physical education lessons. 91 p. 2006.

121 Vuorimaa, Timo, Neuromuscular, hormonal and oxidative stress responses to endurance running exercises in well trained runners. - Neuromuskulaariset, hormonaaliset ja hapettumisstressiin liittyvät vasteet kestävyysjuoksuharjoituksiin hyvin harjoitelleilla juoksijoilla. 93 p. (152 p.) Yhteenveto 3 p. 2007.

122 Mononen, Kaisu, The effects of augmented feedback on motor skill learning in shooting. A feedback training intervention among inexperienced rifle shooters. - Ulkoisen palautteen vaikutus motoriseen oppimiseen ammunnassa: Harjoittelututkimus kokemattomilla kivääriampujilla. 63 p. Yhteenveto 4 p. 2007.

123 Sallinen, Janne, Dietary Intake and Strength Training Adaptation in 50–70 -year old Men and Women. With special reference to muscle mass, strength, serum anabolic hormone concentrations, blood pressure, blood lipids and lipoproteins and glycemic control. - Ravinnon merkitys voimaharjoittelussa 50–70 -vuotiailla miehillä ja naisilla. 103 p. (204 p.) Yhteenveto 3 p. 2007.

124 Kasila Kirsti, Schoolchildren's oral health counselling within the organisational context of public oral health care. Applying and developing theoretical and empirical perspectives. 96 p. (139 p.) Tiivistelmä 3 p. 2007.

125 Pyöriä, Outi, Reliable clinical assessment of stroke patients' postural control and development of physiotherapy in stroke rehabilitation. - Aivoverenkiertohäiriöpotilaiden toimintakyvyn luotettava kliininen mittaaminen ja fysioterapian kehittäminen Itä-Savon sairaanhoitopiirin alueella. 94 p. (143 p.) Yhteenveto 6 p. 2007.

126 Valkeinen, Heli, Physical fitness, pain and fatigue in postmenopausal women with fibromyalgia. Effects of strength training. - Fyysinen kunto, kipu- ja väsymysoireet ja säännöllisen voimaharjoittelun vaikutukset menopaussi-iän ohittaneilla fibromyalgiaa sairastavilla naisilla. 101 p. (132 p.) Yhteenveto 2 p. 2007.

127 Hämäläinen, Kirsi, Urheilija ja valmentaja urheilun maailmassa. Eetokset, ihanteet ja kasvatus urheilijoiden tarinoissa. - An athlete and a coach in the world of sports. Ethos, ideals and education in athletes' narratives. 176 p. Tiivistelmä 2 p. 2008.

128 Aittasalo, Minna, Promoting physical activity of working aged adults with selected personal approaches in primary health care. Feasibility, effectiveness and an example of nationwide dissemination. - Työikäisten liikunnan edistäminen avoterveydenhuollossa – työtapojen toteuttamiskelpoisuus ja vaikuttavuus sekä esimerkki yhden työtavan levittämisestä käytäntöön. 105 p. (161 p.) Yhteenveto 3 p. 2008.

129 Portegijs, Erja, Asymmetrical lower-limb muscle strength deficit in older people. - Alaraajojen lihasvoiman puoliero iäkkäillä ihmisillä. 105 p. (155 p.) Yhteenveto 3 p. 2008.

130 Laitinen-Väänänen, Sirpa, The construction of supervision and physiotherapy expertise: A qualitative study of physiotherapy students' learning sessions in clinical education. - Opiskelijan ohjauksen ja fysioterapian asiantuntijuuden rakentuminen: Laadullinen tutkimus fysioterapiaopiskelijan oppimistilanteista työharjoittelussa. 69 p. (118 p.) Yhteenveto 3 p. 2008.

131 Iivonen, Susanna, Early Steps -liikuntaohjelman yhteydet 4–5-vuotiaiden päiväkotilasten motoristen perustaitojen kehitykseen. - The associations between an Early Steps physical education curriculum and the fundamental motor skills development of 4–5-year-old preschool children. 157 p. Summary 4 p. 2008.

132 Ortega-Alonso, Alfredo, Genetic effects on mobility, obesity and their association in older female twins. 87 p. 2009.

133 Hulmi, Juha, Molecular and hormonal responses and adaptation to resistance exercise and protein nutrition in young and older men. - Voimaharjoittelun fysiologiset ja molekyylibiologiset vaikutukset lihaskasvunsäätelyssä lisäproteiinia nautittaessa tai ilman. 109 p. (214 p.) Yhteenveto 2 p. 2009.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

134 Martinmäki, Kaisu, Transient changes in heart rate variability in response to orthostatic task, endurance exercise and training. With special reference to autonomic blockades and time-frequency analysis. - Sykevaihtelun muutokset ortostaattisessa testissä, kestävyysliikunnassa ja kestävyysharjoittelussa käyttäen hyväksi autonomisen säätelyn salpaus-kokeita ja aika-taajuusanalyysiä. 99 p. (151 p.) Yhteenveto 2 p. 2009.

135 Sedliak, Milan, Neuromuscular and hormonal adaptations to resistance training. Special effects of time of day of training. 84 p. (175 p.) 2009.

136 Nikander, Riku, Exercise loading and bone structure. 97 p. (141 p.) Yhteenveto 1 p. 2009.

137 Korhonen, Marko T., Effects of aging and training on sprint performance, muscle structure and contractile function in athletes. - Ikääntymisen ja harjoittelun vaikutukset nopeussuorituskykyyn, lihasten rakenteeseen ja voimantuotto-ominaisuuksiin urheilijoilla. 123 p. (211 p.) Tiivistelmä 5 p. 2009.

138 Javanainen-Levonen, Tarja, Terveydenhoitajat liikunnanedistäjinä lastenneuvolatyössä. - Public Health Nurses as Physical Activity Promoters in Finnish Child Health Clinics. 104 p. (148 p.) Summary 6 p. 2009.

139 Klemola, Ulla, Opettajaksi opiskelevien vuorovaikutustaitojen kehittäminen liikunnan aineenopettajakoulutuksessa.- Developing student teachers´ social interaction skills in physical education teacher education. 92 p. (138 p.) Summary 4 p. 2009.

140 Niemi, Reetta, Onks tavallinen koe vai sellanen, missä pitää miettii? Ympäristö-lähtöisen terveyskasvatuspedagogiikan kehittäminen narratiivisena toimintatutkimuksena. - Is this a normal test or do we have to think? Developing environmentally oriented health education pedagogy through narrative action research . 215 p. 2009.

141 von Bonsdorff, Mikaela, Physical activity as a predictor of disability and social and health service use in older people. - Fyysinen aktiivisuus toiminnanvajauden ja sosiaali- ja terveyspalvelujen käytön ennustajana iäkkäillä henkilöillä 101 p. (134 p.) Yhteenveto 2 p. 2009

142 Palomäki, Sanna, Opettajaksi opiskelevien pedagoginen ajattelu ja ammatillinen kehittyminen liikunnanopettajakoulutuksessa. - Pre-service teachers' pedagogical thinking and professional development in physical education teacher education. 118 p. (163 p.) Summary 3 p. 2009.

143 Vehmas, Hanna, Liikuntamatkalla Suomessa. Vapaa-ajan valintoja jälkimodernissa yhteiskunnassa. - Sport tourism in Finland – leisure choices in the post-modern society. 205 p. Summary 10 p. 2010.

144 Kokko, Sami, Health promoting sports club. Youth sports clubs' health promotion profiles, guidance, and associated coaching practice, in Finland. 147 p. (230 p.) Yhteenveto 5 p. 2010.

145 Kääriä, Sanna, Low back disorders in the long term among employees in the engineering industry. A study with 5-, 10- and 28-year follow-ups. - Metalliteollisuuden työntekijöiden alaselän sairaudet ikääntyessä: METELI–tutkimuksen 5–, 10– ja 28–vuotisseurantatutkimus. 76 p. (102 p.) Yhteenveto 2 p. 2010.

146 Santtila, Matti, Effects of added endurance or strength training on cardiovascular and neuromuscular performance of conscripts during the 8-week basic training period. - Lisätyn voima- ja kestävyysharjoittelun vaikutukset varusmiesten hengitys- ja verenkiertoelimistön sekä hermo-lihasjärjestelmän suorituskykyyn kahdeksan viikon peruskoulutuskauden aikana. 85 p. (129 p.) Yhteenveto 2 p. 2010.

147 Mänty, Minna, Early signs of mobility decline and physical activity counseling as a preventive intervention in older people. - Liikkumiskyvyn heikkenemistä ennakoivat merkit ja liikuntaneuvonta liikkumisvaikeuksien ehkäisyssä iäkkäillä henkilöillä. 103 p. (149 p.) Yhteenveto 2 p. 2010.

148 Rantalainen, Timo, Neuromuscular function and bone geometry and strength in aging. - Neuromuskulaarinen suorituskyky luun geometrian ja voiman selittäjänä ikääntymisen yhteydessä. 87 p. (120 p.) Yhteenveto 1 p. 2010.

149 Kuitunen, Sami, Muscle and joint stiffness regulation during normal and fatiguing stretch-shortening cycle exercise . - Lihas- ja niveljäykkyyden säätely normaalin sekä väsyttävän venymis-lyhenemissyklityyppisen harjoituksen aikana . 76 p. (142 p.) Yhteenveto 1 p. 2010.

150 Piitulainen, Harri, Functional adaptation of sarcolemma to physical stress. - Lihassolukalvon toiminnallinen mukautuminen fyysiseen kuormitukseen. 103 p. (178 p.) Yhteenveto 2 p. 2010.

151 Viljanen, Anne, Genetic and environmental effects on hearing acuity and the association between hearing acuity, mobility and falls in older women. - Kuulon tarkkuuden periytyvyys ja yhteys liikkumiskykyyn sekä kaatumisiin iäkkäillä naisilla. 85 p. (116 p.) Yhteenveto 2 p. 2010.

152 Kulmala, Jenni, Visual acuity in relation to functional performance, falls and mortality in old age. - Heikentyneen näöntarkkuuden vaikutus toimintakykyyn, kaatumisiin ja kuolleisuuteen iäkkäillä henkilöillä. 98 p. (140 p.) Yhteenveto 3 p. 2010.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

153 Nivala, Sirkka, Kokemuksellinen vanheneminen sotainvalideilla. Suomalaisten sotainvalidien kokemus elämänkulustaan ja ikääntymisestään. - Disabled war veterans and experiential ageing. Finnish disabled war veterans and their experience of the course of their lives and growing older. 178 p. Summary 4 p. 2010.

154 Rinne, Marjo, Effects of physical activity, specific exercise and traumatic brain injury on motor abilities. Theoretical and pragmatic assessment. 86 p. (134 p.) Tiivistelmä 2 p. 2010.

155 Mikkola, Tuija, Genetic and environmental contributions to bone structural strength in postmenopausal women. - Perimän ja ympäristötekijöiden vaikutus luun lujuuteen vaihdevuosi-iän ohittaneilla naisilla. 77 p. (130 p.) Yhteenveto 2 p. 2010.

156 Salo, Petri, Assessing physical capacity, disability, and health-related quality of life in neck pain. 93 p. (132 p.) Yhteenveto 2 p. 2010.

157 Ronkainen, Paula, Towards powerful old age. Association between hormone replacement therapy and skeletal muscle. - Vaihdevuosioireisiin käytettävän HRT:n yhteys luurankolihaksiston rakenteeseen ja toimintaan. 118 p. (170 p.) Yhteenveto 2 p. 2010.

158 Kilpikoski, Sinikka, The McKenzie method in assessing, classifying and treating nonspecific low back pain in adults with special reference to the centralization phenomenon. - McKenzien mekaaninen diagnostisointi- ja terapiamenetelmä tutkittaessa, luokiteltaessa ja hoidettaessa aikuisten epäspesifiä alaselkäkipua. 90 p. (130 p.) Yhteenveto 2 p. 2010.

159 Mutikainen, Sara, Genetic and environmental effects on resting electrocardiography and the association between electrocardiography and physical activity, walking endurance and mortality in older people. - Lepo-EKG –muuttujien periytyvyys sekä yhteydet fyysiseen aktiivisuuteen, kävelykestävyyteen ja kuolleisuuteen iäkkäillä henkilöillä. 84 p. (131 p.) Yhteenveto 3 p. 2010.

160 Völgyi, Eszter, Bone, fat and muscle gain in pubertal girls. Effects of physical activity. 76 p. (138 p.) Tiivistelmä 1 p. 2010.

161 Sillanpää, Elina, Adaptations in body composition, metabolic health and physical fitness during strength or endurance training or their combination in healthy middle-aged and older adults. 113 p. (179 p.) Yhteenveto 3 p. 2011.

162 Karavirta, Laura, Cardiorespiratory, neuromuscular and cardiac autonomic adaptations to combined endurance and strength training in ageing men and women. - Yhdistetyn kestävyys- ja voimaharjoittelun vaikutukset hengitys- ja verenkiertoelimistön sekä hermo-lihasjärjestelmän toimintaan ja sydämen autonomiseen säätelyyn ikääntyvillä miehillä ja naisilla.108 p. (178 p.) Yhteenveto 2 p. 2011.

163 Hynynen, Esa, Heart rate variability in chronic and acute stress with special reference to nocturnal sleep and acute challenges after awakening. - Sykevariaatiomittaukset kroonisen ja akuutin stressin seurannassa käyttäen hyväksi yöunen ja akuuttien tehtävien aikaisia vasteita. 74 p. (109 p.) Yhteenveto 3 p. 2011.

164 Pavelka, Béla, Open Water as a Sportscape. Analysis of canoeing in Finland for developing sport infrastructure and services. 116 p. 2011.

165 Pesonen, Jyri, Opettajat oppijoina. Toimintatutkimus liikunnanopettajien pätevöittämiskoulutuksen käynnistämisestä ja kehittämisesestä. - Teachers as learners – An action research on starting the development of qualifying training for teachers of physical education. 204 p. Summary 4 p. 2011.

166 Borremans, Erwin, Asperger syndrome and physical exercise. A study about sensomotor profiles, physical fitness, and the effectiveness of an exercise training program in a group of adolescents with Asperger syndrome. 111 p. (181 p.). Yhteenveto 3 p. 2011.

167 Ojala, Kristiina, Nuorten painon kokeminen ja laihduttaminen – Health Behaviour in School-aged Children (HBSC) study ja WHO-Koululaistutkimus. - Adolescents' self-perceived weight and weight reduction behaviour - Health Behaviour in School-aged Children (HBSC) study, a WHO Cross-National Survey. 151 p. (203 p.) Summary 4 p. 2011.

168 Rantakokko, Merja, Outdoor environment, mobility decline and quality of life among older people. - Ulkoympäristötekijät, ulkona liikkumisen heikkeneminen ja elämänlaatu iäkkäillä ihmisillä. 86 p. (119 p.) Yhteenveto 3 p. 2011.

169 Pöllänen, Eija, Regulation of gene expression and steroidogenesis in skeletal muscle of postmenopausal women - With emphasis on the effects of hormone replacement and power training. 114 p. (182 p.) Yhteenveto 2 p. 2011.

170 Yli-Piipari, Sami, The development of students' physical education motivation and physical activity. A 3.5-year longitudinal study across grades 6 to 9. - Koululaisten koululiikuntamotivaation ja fyysisen aktiivisuuden kehitys. 3.5 vuoden pitkittäistutkimus alakoulusta yläkouluun. 107 p. (218 p.) Yhteenveto 2 p. 2011.

171 Bottas, Reijo, Motor control of fast voluntary elbow movements. Exercise-induced muscle damage and soreness and learning interventions. - Kyynärvarren nopeiden tahdonalaisten liikkeiden motorinen kontrolli harjoituksessa aiheutetun lihassoluvaurion ja lihaskivun sekä oppimisen interventiona. 95 p. (206 p.) Yhteenveto 1 p. 2011.

STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH

172 Ma, Hongqiang, Adaptation of bone to physical activity and diet-induced obesity. - Luun mukautuminen fyysiseen aktiivisuuteen ja ravinnon aikaansaamaan lihavuuteen. 146 p. (197 p.) Yhteenveto 1 p. 2011.

173 Paatelma, Markku, Orthopedic manual therapy on low back pain with working adults; clinical tests, subclassification and clinical trial of low back pain. 98p. (131 p.) Tiivistelmä 2 p. 2011.

174 Saari, Aija, Inkluusion nosteet ja esteet liikuntakulttuurissa. Tavoitteena kaikille avoin liikunnallinen iltapäivätoiminta. - Promotors and hindrances of inclusion in sports and physical activity – aiming at open-for-all after-school activities. 175 p. Summary 6 p. 2011.

175 Waller, Katja, Leisure-time physical activity, weight gain and health – A prospective follow-up in twins. - Vapaa-ajan liikunta, painonnousu ja terveys - yli 20 vuoden seurantatutkimus kaksosilla. 88 p. (120 p.) Yhteenveto 3 p. 2011.

176 Xu, Leiting, Influences of muscle, fat and hormones on bone development in women. A cross-sectional and longitudinal study spanning three generations. 68 p. (98 p.) Tiivistelmä 1 p. 2011.

177 Lihavainen, Katri, Mobility limitation, balance impairment and musculoskeletal pain among people aged ≥ 75 years: A study with a comprehensive geriatric intervention. - Iäkkäiden henkilöiden kipujen yhteys liikkumiskykyyn ja tasapainon hallintaan sekä laaja-alaisen geriatrisen intervention vaikutukset liikkumiskykyyn. 90 p. (133 p.) Yhteenveto 2 p. 2012.

178 Pakkala, Inka, Depressive symptoms, sense of coherence, physical activity and genetic factors among older people. - Masentuneisuus, koherenssi, fyysinen aktiivisuus ja geneettiset tekijät ikääntyneillä ihmisillä . 95 p. (142 p.) Yhteenveto 3 p. 2012.

179 Paakkari, Leena, Widening horizons: A phenomenographic study of student teachers' conceptions of health education and its teaching and learning. 106 p. (158 p.) Yhteenveto 2 p. 2012.

180 Sallinen, Merja, Women's narratives on fibromyalgia, functioning and life events. - Naisten elämäntarinallisia kokemuksia fibromyalgiasta, toimintakyvystä ja elämäntapahtumista. 68 p. (119 p.) Yhteenveto 5 p. 2012.