Balancing intrusive illness:
The experiences of people with musculoskeletal problems

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DISSERTATIONS FROM THE DEPARTMENT OF NURSING,
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The overall aim of the present thesis was to explore and describe the health experiences of men and women with musculoskeletal problems. The specific aims of the four papers were: (I) to explore the experience of illness and wellness among ambulance personnel with musculoskeletal symptoms; (II) to explore the experience of illness and wellness among female health care personnel with musculoskeletal symptoms; (III) to explore the experience of bodily illness among people with musculoskeletal problems in the neck-shoulder region, and; (IV) to investigate the symptoms described by people with non-specific neck-shoulder problems, to investigate the method of development of neck-shoulder questionnaires that assesses pain and other symptoms, to analyse the content and items of these questionnaires, and to compare the findings from the analyses of the interviews and the questionnaires.

The overall findings show that the occupationally active men and women with MSDs were “striving for balance” (I-II), that the disease course of chronic neck-shoulder disorders was characterised by “uncontrollable fluctuations” (III), and that most neck-shoulder questionnaires had a low correspondence to the variety of symptoms experienced during this course (IV).

In the process of striving for balance (I-II), the informants’ health experiences were not a state of either wellness or illness, but of both, in varying degrees at different times. The balancing started when illness became too intrusive, and was a process of minimising the impact of illness by accepting and handling it, while attaining and maintaining wellness to feel well enough. When striving for balance, the interviewees kept on working to continue being nurtured at the same time as they made different efforts directed at minimising the impact of their illness. For both men and women, illness was characterised by disembodiment, vulnerability, and exhaustion. The illness experiences were counterbalanced by wellness, where some differences could be recognised between the men and the women.

Study III further explored the experiences of bodily illness, focusing on people with chronic musculoskeletal disorders in the neck-shoulder region. The course of the disorder was described as characterised by uncontrollable fluctuations, and it usually developed from insidious symptoms to a state of constant discomfort. The participants experienced calmer
periods during the course, but intermittent events of increasing illness were always lying in wait, with periodic moments of consuming intensity.

In the interviews included in study IV a variety of symptoms were expressed, which indicated a bodily, mental, and emotional engagement, which included more general and more severe symptoms than are usually related to neck-shoulder disorders. Few of the questionnaires were developed using the experiences of the affected. Taken as a whole, did the questionnaires cover many of the symptoms of the interviewees, but each individual questionnaire only included a few. The fluctuations and nuances of symptoms were rarely considered. The correspondence between individual questionnaires and the experiences of those affected was most often low.

This thesis reveals other aspects of health than just bodily experiences as important among occupationally active people with MSDs. It also provides a description of the disease course, and an indication of possibilities for improvement of neck-shoulder questionnaires.

**Key words:** musculoskeletal problems, health experiences, illness, wellness, grounded theory, content analysis, balancing, disease course, uncontrollable fluctuations, symptoms.
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


III. Wiitavaara, B., Brulin, C. & Barnekow-Bergkvist, M. When the body makes itself heard – the experience of bodily illness among people with neck-shoulder problems. (Submitted.)

IV. Wiitavaara, B., Björklund, M., Brulin, C. & Djupsjöbacka, M. How well do neck-shoulder questionnaires capture the experiences of those who suffer of neck-shoulder problems? –A comparison between questionnaires and interviews. (Manuscript.)

Papers are reprinted by kind permission of the respective journals.
The making of this thesis, and the research behind it, is a result of coincidences and meetings between people, as with so much else in life. During my master’s course at the Department of Nursing in Umeå I met my future head supervisor, Associate Professor Christine Brulin, who was in ongoing discussion with Professor Håkan Johansson at the Centre for Musculoskeletal Research about the usefulness of qualitative methods in musculoskeletal research. So, when Professor Johansson initiated the project of which this thesis forms a part, Associate Professor Brulin was the link between him and me. My background was thus not one of clinical experience or special knowledge in the area of musculoskeletal research, but of being interested in qualitative research methods and having some skills in it.

Despite the large amount of research in the area of musculoskeletal disorders (MSDs), the problem is far from being completely charted, and the disorders still constitute a significant problem from both an individual and a social perspective. Musculoskeletal disorders are mostly approached from an outside perspective, and using quantitative methodology. Since current measures for prevention, treatment, and rehabilitation have not produced adequate results, there is a need for further research in the area. The starting point of this thesis was the supposition that it can be useful to turn to the affected to find out which aspects are most important as subjects of study. This thesis presents experiences ranging from a holistic picture of the health experiences, to the disease course, and finally down to the level of the symptoms.

I have worked as a registered nurse for many years. Over this time, I have found my role as the patient’s advocate to be a very important aspect of my work. Working with qualitative research methods, and thereby trying to make visible the experiences of the affected, has been a natural continuation of the same task. I am very grateful to all the women and men who so openly shared parts of their lives and experiences with me. The need for someone who will listen, and the hope of obtaining help, were obvious, spoken and unspoken. While winding down at the end of the interviews, the informants often commented along the following lines: “I had hoped for some help when I agreed to participate”… but if I cannot get it now, this will hopefully help someone in the future”. I hope that I can live up to these expectations, and that this thesis can make its contribution to the area of musculoskeletal research.
BACKGROUND

The presentation of a thesis on experiences of musculoskeletal disorders requires a number of clarifications; not only must we describe the theoretical perspective and framework that were used in the research, and define the subject of research, but it is also necessary to discuss a number of other aspects which emerge as important for better interpretation and understanding of the findings.

Theoretical framework

Symbolic interactionism

A theoretical perspective contains a number of fundamental conceptions about reality; these conceptions also help us to make sense of the social reality we are trying to understand. One such theoretical perspective is symbolic interactionism (Blumer, 1969; Mead, 1934), the ancestor of grounded theory. The cornerstones of this perspective are: the definition of the situation (situations defined as real are real in their consequences) (Thomas & Thomas, 1928); all interaction is social; we interact using symbols; man is active, and we act, behave, and exist in the present (Trost & Levin, 1999). In other words, people act toward things based on the meaning those things have to them. The meanings of things, in turn, arise out of social interaction between people, and these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he or she encounters (Blumer, 1969). So, in a symbolic interactionist perspective, the meaning of reality is constructed. Similarly, in the present thesis, meanings of things (as health experiences) are seen to arise, and to be modified and handled in social interaction in specific contexts.

Gender theories

Taking gender into account further adds to the understanding of health experiences, as different societies with their different groups and cultures can influence the shaping of bodies, as well as health, disease, and illness, and the ways in which they are experienced (e.g. Courtenay, 2000; Courtenay & Keeling, 2002; Freund, McGuire & Podhurst, 2003). People are encouraged to conform to stereotyped beliefs and behaviours, and to adopt the dominant norms of femininity and masculinity (e.g. Bohan, 1993). Power and status are key concepts in gender, as gender is negotiated in part through relationships of power (Courtenay, 2000). Harding (1986) describes the gender system as being divided into three components: a symbolic system with different and opposite characteristics assigned to women and men.
(passive/active, dependent/independent); a structural system with the division of labour organised according to the symbolic system; and an individual system in which personal identity is formed by social opinions of what is appropriate for women and for men. West and Zimmerman (1987) argue that gender is not something we are; instead, we are “doing gender”. Gender is continually reconstructed, adapting to appropriate female and male conceptions in different social and cultural contexts, resulting in a range of different masculinities and femininities (e.g. Butler, 1990; Connell, 1995; Connell & Messerschmidt, 2005; Courtney, 2000). As women and men, we are continuously “doing gender” in all walks of life and all contexts — and so also were the informants participating in these studies, hence a consideration of gender aspects was useful in the interpretation of their health experiences.

Emotion theories

During the work of this thesis, emotion theory emerged as a tool for interpreting the health experiences of people with MSDs, in terms of creating a better understanding of the parts of the process and the connection between different aspects. Emotion theory has been suggested to provide a basis from which to approach health and illness, constituting a holistic paradigm which overcomes the artificial divisions between body, mind, and society (e.g. Carpenter, 2000; Freund et al., 2003). Prior to the development of emotion theory, sociology often viewed people as disembodied, and the role of emotion in social life was similarly neglected. Emotion theory has now emerged as a major area of investigation; it views humans as cognitive, active, as well as constrained agents. Its aim is to connect psychological processes and social relations to the somatic or bodily processes within which emotions are embedded (Freund et al., 2003; Williams & Bendelow, 1996). The informants in the first two studies comprising this thesis expressed experiences that included all these aspects; interpreting them using emotion theory made the parts fall into place, and the connections in between became understandable.

Emotions are essential to notions of embodiment, which is the way in which people live and experience their bodies (Lupton, 1998). While bodily states are complex intertwinings of anatomy and society/culture, emotional states “serve to bring together nature and culture in a seamless intermingling in which it is difficult to argue where one ends and the other begins” (Lupton, 1998 p.82). Barbalet (1999) has proposed that emotions include a physiological component of arousal or bodily sensation, as well as the subjective component of feelings and the impulsive or motor component of expressive gesture. Emotion has been described as
embodied thoughts which are felt in our minds, hearts, stomachs, and skin (Rosaldo, 1984). There is no consensus on what is, or is not, an emotion, but Plutchik (1994) has described fear, anger, sadness, joy, acceptance, disgust, anticipation, and surprise as being primary emotions.

**Views of health**

Increasing the understanding of MSDs, or indeed other states of ill health, requires all dimensions of the health experiences to be taken into consideration. In making a distinction between different health definitions, it is customary to distinguish between negative, positive, functional and experiential definitions of health (Calnan, 1987). The medical view (health as absence of disease) is clearly negative, while for example the definition offered by WHO (1948) (a state of complete physical, mental, and social well-being) is positive. A functional definition implies the ability to participate in normal social roles and activities (Parsons, 1979), and this may be contrasted with an experiential definition, which takes sense of self into account (Kelman, 1975). Research on musculoskeletal disorders has mostly used a negative, functional definition of health.

The dimensions of health, disease, illness, and wellness have also been described as being closely related; they are part of the same process, and are neither mutually exclusive nor completely opposed (Jensen & Allen, 1993). A continuous shift in perspective, between illness in the foreground and wellness in the foreground, has been described among people with chronic illness (Paterson, 2001). As illness and wellness emerged as interrelated concepts which together constituted the personal health experiences of the informants, both are in focus in this thesis.

Conrad (1987) makes a number of important distinctions regarding illness experiences and focus in research into them. He starts by making a conceptual distinction between disease as an undesirable physiological process, and illness as the social and psychological phenomenon that encompasses these physiological problems. He notes that there can be disease without illness, as well as illness without disease. Research on illness experiences can have an insider’s or an outsider’s orientation. Classic examples of the outsider perspective are the writings on sick-role (Parsons, 1951), and illness-behaviour (Mechanic, 1962). The outsider approach to illness is often deductive, and takes the view of the provider, while the insider approach focuses specifically on the perspectives of people with illness, examining the illness
experience more inductively. Conrad (1987) notes that such a perspective focuses on “the meaning of illness, the social organisation of the sufferer’s world, and the strategies used in adaptation” (p. 5). It also confronts the question of illness, self-perception, and self-worth. When using an insider perspective, it is also important to turn away from the provider-patient focus by re-conceptualising the respondents as “sufferers” or “people with…”, rather than patients. An awareness of the ways that illness experiences vary in relation to historical period and culture, as belief systems vary, is also fundamental.

Well-being and quality of life represent the subjective perceptions, judgements, and expectations of individuals about their health. These multidimensional concepts encompass physical, psychological, and spiritual aspects of health. There is no consensus about these definitions, and the terms “quality of life”, “well-being”, and “wellness” are often used interchangeably in the literature (Haas, 1999). Sarvimäki (2006) argues that “well-being, health and quality of life may be seen as three basic concepts — maybe the basic concepts — in public health and other health sciences” (p.4), even though there is no unanimous definition of the concepts and no common view of how they relate to each other. Further, as indicated by an overview of different definitions and models, she states that well-being may well be conceived as a unifying concept and a characteristic of both health and quality of life (Sarvimäki, 2006). Dunn (1961) formally defined wellness as “an integrated method of functioning which is oriented towards maximizing the potential of which the individual is capable” (p.4). According to Coward and Reed (1996), wellness reflects a sense of well-being that is derived from an intensified awareness of wholeness and integration among all dimensions of one’s being; it is also supposed to include the spiritual elements of life. Adams, Bezner and Steinhardt (1997) defined wellness as a sense of living in a way that permits experiences of consistent, balanced growth in the emotional, intellectual, physical, psychological, social, and spiritual dimensions of human existence. By this, they mean that there are three principles common to all conceptualisations of wellness: multidimensionality, balance among dimensions, and salutogenesis (Adams, Bezner, Drabbs, Zambarano & Steinhardt, 2000).

According to Kristofferson, Nortvedt and Skaug (2006) has the focus of nursing been described as being the care of the sick person (Kari Martinsen, Katie Eriksson, Patricia Benner), and the fundamental needs of the human being (Virginia Henderson, Dorothea Orem), and the mission is to cure, alleviate, and console. This requires knowledge both from
an outside perspective (logical-scientific, cause-effect, explaining-predicting) and an inside perspective, to get insight into and understanding of the experiences and meanings related to being ill. According to the International Council of Nurses (ICN, 2007), nursing encompasses the care of individuals of all ages, families, groups, and communities, whether sick or well, in all settings. Nursing is said to include promotion of health, prevention of illness, and the care of ill, disabled, and dying people. This thesis searches out knowledge from an inside perspective of the experiences of people affected by MSDs. An increased knowledge of the fundamental needs and illness experiences related to this illness is needed to promote health, to prevent illness, and to cure, alleviate, and console.
**Musculoskeletal disorders**

**Definitions**

In musculoskeletal research, the term “disorders” is used as a descriptor for pathological entities in which the functions of the musculoskeletal system are disturbed or abnormal. According to Kuorinka and Forcier (1995), disorders can be contrasted with diseases, which are considered to be defined pathological entities having observable impairments in body configuration and function. According to the American National Institute for Occupational Safety and Health (NIOSH), the term “musculoskeletal disorders” refers to conditions that involve the nerves, tendons, muscles, and supporting structures of the body (Bernard, 1997). Body maps are often used to specify the location and spread of symptoms when measuring musculoskeletal disorders.

![Figure 1. Body map](image)

N = Neck
S = Shoulder
LB = Low back
The neck, shoulder, and low back are the regions most often chosen for study, but studies involving the knees, hips, elbows, and other joint areas can also be found. There are also a few differentiations that can be made within the class of neck-shoulder disorders; firstly regarding whether the origin or cause of the problem is known or not (idiopathic or clearly diagnosed), and secondly regarding whether the disorder is traumatic (e.g. whiplash) or non-traumatic.

There is no consensus in use of terms to describe musculoskeletal disorders and symptoms related to musculoskeletal disorders. Musculoskeletal/muscular disorders, problems, complaints and pain, for example, are often used interchangeable. Kleinman (1988) distinguishes between “illness problems” and “illness complaints”; illness problems are practical difficulties caused by illness, while illness complaints are the complaints that the individual brings to the practitioner, which may or may not include illness problems. In addition, choosing symptoms may often indicate a solely physical focus of the study. In this thesis I have made an effort to use the different terms in a consistent way, even though I may not have succeeded all the way, as my consciousness has grown during my work. The term “disorders” is used when referring to previous research and to define the conditions. “Musculoskeletal problems” is used in order to indicate that the focus is the experiences of the sufferer, although it is not narrowed to only include practical difficulties, as defined by Kleinman (1988). “Symptoms” is used when referring directly to the bodily, mental and emotional experiences the informants experienced. However, the terms “discomfort”, “fatigue”, and “pain” are widely used to describe the experiences of bodily illness in MSDs, as they are recognised as the most common initial symptoms associated with the condition (Kuorinka et al., 1987; Kuorinka & Forcier, 1995). Discomfort is often defined as physical or mental distress, and is used as a synonym for inconvenience, which indicates a perceptual, subjective phenomenon that is more diffuse than pain. Fatigue has been defined as a lack of the capacity to continue strenuous physical or mental work to the same extent as previously; that is, it is an unwanted, transient sensation that influences the individual’s motivation and capacity (Kuorinka & Forcier, 1995). Fatigue has also been summarised as changes in three main functions: bodily changes, performance changes, and perceptual changes (Åhsberg, 1998). Pain has been defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage; it has previously been described in terms of such damage (IASP, 1979).
Measurement of musculoskeletal disorders

There are a great number of instruments in use for measuring the prevalence of musculoskeletal disorders and the effects of rehabilitation programmes. Most often, a questionnaire measures only one or two aspects of the musculoskeletal problem, for example prevalence, pain location, intensity and duration of pain, disability (the interference of pain with life activities), kinesiophobia (the fear that physical activity will exacerbate the problem), self-efficacy (confidence in accomplishing different tasks and activities), or physical exertion. Hence, it is often necessary to use a combination of several questionnaires which focus on different aspects of musculoskeletal disorders in order to cover the entire range of relevant factors. There might be a lack of condition-specific questionnaires aimed at investigating the specific manifestations of symptoms related to a particular musculoskeletal condition, for example neck-shoulder disorders.

Comparison between studies and evaluation of the results of treatment are both hindered by the great variability in outcome measures used across clinical trials for chronic pain. In order to overcome this problem, Dworkin et al., (2005) recommend six core outcome domains to consider when designing clinical trials: pain, physical functioning, emotional functioning, global improvement, satisfaction with treatment, symptoms and adverse events. Further, they point out the value of investigating different quality and temporal aspects of pain, as various measures of these components can more fully describe a patient’s pain experience than would be possible using pain intensity alone.

There are a number of different ways to develop questionnaires for musculoskeletal disorders. Often, the sources of items for new questionnaires are existing questionnaires, health professionals, and published literature (Bombardier & Tugwell, 1987). There is, however, increasing consensus regarding the value of taking the experiences of the affected into consideration in the development of health status measurements (Bombardier & Tugwell, 1987; Guyatt, Feeney & Patrick, 1993; Hoving, O'Leary, Niere, Green & Buchbinder, 2003; Streiner & Norman, 1995). Despite this consensus, the practice is rare in the area of musculoskeletal disorders, and a number of researchers have highlighted the need for further analysis of the items included in fixed-item questionnaires (Hoving et al., 2003; Pietrobon, Coeytaux, Carey, Richardson & DeVellis, 2002). There is, therefore, a need to investigate the experiences of persons with musculoskeletal pain in order to make it possible to increase the validity of questionnaires for musculoskeletal disorders.
Prevalence of musculoskeletal disorders

Musculoskeletal disorders are primarily a source of pain and human suffering, but they also have economic consequences, both for the individual and for society. The yearly costs of health care, sick leave, and preterm retirement due to musculoskeletal disorders are estimated to be about three times as high as the corresponding costs of, for example, all cancer diseases (SBU, 2000). The prevalence of musculoskeletal disorders is high, although the numbers vary greatly between different studies due to differences in study design, study population, and the definition of the disorder and its anatomical location (SBU, 2006; Shelerud, 2006). Different time aspects are also used in the prevalence rates. Point prevalence is the proportion of a group that has the measured problem at the point of data collection. Chronic complaints are usually defined as those which persist longer than three or six months. Finally, lifetime prevalence measures the proportion of people who have suffered from the relevant problem at some point during their life.

Pain in the low back and neck is common. As much as 80% of the Swedish population are affected by low back pain at some point in life, and 50% are affected by neck pain; these figures are comparable to international prevalence figures, which show a lifetime prevalence of 60–70% for low back pain and 67–71% for neck pain (SBU, 2000). The corresponding proportions for point prevalence were 15–30% for low back pain and 12–22% for neck pain. Similar results for point prevalence were also found in a number of recent studies; 19% for low back pain (Suka & Youshida, 2005), 21–43% for neck pain (Guez, Hildingsson, Nilsson & Toolanen, 2002; Picavet & Schouten, 2006) and 20% for neck-shoulder pain (Suka & Youshida, 2005).

The prevalence of chronic complaints has been estimated at 22% for the low back (Wijnhoven, de Vet & Picavet, 2006) and 16–19% for the neck (Guez et al., 2002; Wijnhoven et al., 2006). There are differences between the sexes; for example, there is a systematically higher prevalence of musculoskeletal disorders among women, independent of localisation of problem or the period the prevalence was accessed (Statistics Sweden, SCB, 2007; Wijnhoven et al., 2006).

Another measurement of prevalence is the effect of MSDs on sick leave figures; 44% of work-related sick leave in Sweden during 2000–2002 was caused by MSD (Statistics Sweden, SCB, 2004).
Some occupational groups are considered to be more affected than others; among them are health care personnel such as nurses, nurses’ aides, and ambulance personnel. The prevalence of self-reported MSDs in any part of the body has been reported to be as high as 62–89% in various studies carried out in nursing personnel (Eriksen, 2003; Menzel, Brooks, Bernard & Nelson, 2004; Smith, Ohmura, Yamagata & Minai, 2003; Smith, Wei, Kang & Wang, 2004). In addition, among health care personnel, ambulance personnel have the highest percentage of early retirement, often due to musculoskeletal disorders (Pattani, Constantinovici & Williams, 2001; Rodgers, 1998a, b; Sterud, Ekeberg & Hem, 2006).

**Risk factors for musculoskeletal disorders**

There is, overall, an international consensus of which risk factors relate to musculoskeletal disorders. Physical factors, alone or in combination with psychosocial and individual factors, are seen as contributing, to the development of MSDs (Punnett & Wegman, 2004; SBU, 2006; Westgaard, 1999). For example, heavy lifting, frequent bending and twisting, non-neutral postures, and vibration, as well as different aspects of poor psychosocial conditions such as high demands and limited control over one’s one work, are often reported to be physical and psychosocial risk factors for low back pain. For neck-shoulder pain, the commonly cited physical risk factors are repetitive arm movements, static load of the neck region, and insufficient recovery time; these are often reported together with psychosocial risk factors such as high demands, limited control over one’s work, and low satisfaction with work. In addition, individual factors such as age, gender, work capacity, and socio-economic status might modify the effects of different physical and psychosocial risk factors.

**Experiences of living with musculoskeletal disorders**

Living with musculoskeletal disorders has been described by those affected as “meeting an unpredictable threat”, and as “a bizarre invader” (Johansson, Hamberg, Westman & Lindgren, 1999). The invasive character of the disorder has been elucidated in different negative experiences related directly to the body, such as a loss of bodily control (Johansson et al. 1999), a deconstructed body, and bodily constraints (Dysvik, Natvig, Eikeland & Lindstrøm, 2005; Johansson et al. 1999; Miles, Curran, Pearce & Allan, 2005), which in turn lead to activity constraints (Miles et al., 2005; Walker, Sofaer & Holloway, 2006). Negative experiences have also been related to the individual’s identity, self-perception, and self-esteem (Busch, 2005; Dysvik et al. 2005; Harding, Parsons, Rahman & Underwood, 2005; Johansson et al. 1999; Miles et al. 2005; Walker et al., 2006; Werner, Isaksen & Malterud, 2005).
2004; Werner & Malterud, 2003), as it becomes impossible to lead one’s life as before. As MSDs lacks defined pathological entities, standardised measurements, and observable impairments in body configuration and function, living with the disorder and seeking help have also been described as a struggle to be believed, understood, and taken seriously (Glentorn, 2003; Johansson, Hamberg, Lindgren & Westman, 1996; Johansson et al., 1999; Lillrank, 2003; Walker, Holloway & Sofaer, 1999; Werner et al., 2004; Werner & Malterud 2003). Neglectful attitudes from people in health care, at work, at home, and within other, less close, relationships can become part of the problem; therefore, to finally be diagnosed and taken seriously can be experienced as a great relief (Lillrank 2003). The disorder also involves other losses for the person affected; both financially, since working to the same extent as before becomes hard or impossible (Walker et al., 2006), and socially, such as losing the camaraderie of work, and other social networks (Espvall & Olofsson, 2002; Walker et al., 2006). “Work to the end of the road” is presented as a strategy used in relation to MSDs and work (Hansson, Boström & Harms-Ringdahl 2006), as well as experiences of a duty to work (Östlund, Cedersund & Hensing, 2002). This intrusion in life necessitates finding different ways of living (Hansson et al., 2001; Harding et al., 2005; Walker et al., 1999), and ways of coping despite the pain (Hansson et al., 2006; Harding et al., 2005; Walker et al., 1999). Most of these studies present the social aspects of living with musculoskeletal disorders, as described by persons living with the disorder; only a few focuses on experiences of the body, and even these take an existential point of view.

Rationale for the study
Musculoskeletal disorders are a significant problem, both from a societal perspective and from the personal perspective of those affected. MSDs are one of the main causes of the high prevalence of long-term sick leave and pre-term retirement that we see today (see e.g. AFA 2004; Pattani et al., 2001; SBU, 2000, 2006; Swedish Work Environment Authority & SCB, 2003). Despite great efforts to diminish the proportion of people on sick leave or pre-term retirement through preventive and rehabilitative measures, the expected result has not been accomplished. One reason for this could be that the main body of research in the area has a biomedical and/or medical perspective, and only a minor part focuses on the experiences of the affected. Furthermore, almost all studies concern people who are severely affected by musculoskeletal symptoms and thus have been on long-term sick leave or have taken pre-term retirement. To be able to prevent, treat, and rehabilitate MSDs at an early stage, it is necessary to take into account personal health experiences, especially those of people with minor
problems who are still active in working life. Additionally, as there are differences between men and women in prevalence and factors contributing to the development of MSD (e.g. Bongers, Ijmker, van den Heuvel & Blatter, 2006; Bot et al., 2005; Harkness, Macfarlane, Silman & McBeth, 2005, Leroux, Dionne, Bourbonnais & Brisson, 2005; Shelerud, 2006; Wijnhoven et al., 2006), it is important to describe the experiences of both women and men. Furthermore, typically female-dominated and male-dominated occupations are both represented among the high risk group for MSDs, which gives support to our choice to focus our research among those occupational groups in order to find people with MSDs who are still active in working life. Thus, the first two studies included in this thesis turned to women in a female-dominated milieu (different acute care wards), and men in a male-dominated milieu (the ambulance service).

The process of developing MSDs has not previously been described other than in terms of the general disease course (Kuorinka & Forcier, 1995). However, there are some recent studies which aim to examine and describe the natural, individual, or clinical course of neck-shoulder disorders (Aublet-Cuvelier, Aptel & Weber, 2006; Bot et al., 2005; Pernold, Mortimer, Wiktorin, Tornqvist & Vingård, 2005). The data in these studies was gathered via questionnaires or clinical examinations, and the results indicate that the disorder is persistent, with low recovery rates. The bulk of improvement was seen after 3 months, with only minor improvements occurring thereafter (Bot et al., 2005; Pernold et al., 2005). The authors discuss the disease course as having a great variability, including recurring symptoms (Aublet-Cuvelier et al., 2006; Bot et al., 2005). However, the disease course is not fully described in detail, using the experiences of the affected. To treat people with musculoskeletal disorders effectively, it is crucial to know more about the disease course and the symptoms involved in it, in order to be able to make a correct diagnosis, to treat the sufferer, and to evaluate the effects of the treatment. The obvious next step is to further explore the experiences of people with MSDs during the disease course.
AIM OF THE STUDY

The overall aim of the present thesis was to explore and describe the health experiences of men and women with musculoskeletal problems.

The specific aims of the four papers were:

**Paper I:**
To explore the experience of illness and wellness among ambulance personnel with musculoskeletal symptoms.

**Paper II:**
To explore the experience of illness and wellness among female health care personnel with musculoskeletal symptoms.

**Paper III:**
To explore the experience of bodily illness among people with musculoskeletal problems in the neck-shoulder region.

**Paper IV:**
To investigate the symptoms described by people with non-specific neck-shoulder problems,
To investigate the method of development of neck-shoulder questionnaires that assesses pain and other symptoms
To analyse the content and items of the questionnaires
To compare the findings
METHODOLOGICAL FRAMEWORK

Grounded theory
Study I-III relies on the methodological assumptions of grounded theory (Glaser, 1978, 1992; Glaser & Strauss, 1967). Grounded theory has its roots in sociology and symbolic interactionism (Blumer, 1969; Mead, 1934), which provide the philosophical foundation that guides the research process. Mead (1934) stated that people define themselves through social interaction with others in the forms of social roles, expectations, and learned perspectives. Grounded theory research is aimed at understanding how a group of people define, through social interaction, their own reality (Stern, 1980); thus, the task of the researcher is to discover and conceptualise the essence of complex interactional processes (Hutchinson & Skodol Wilson, 2001). The grounded theory method was initially developed by two sociologists, Glaser and Strauss, in the 1960s. Since the publication of their book on the method, “The discovery of grounded theory”, in 1967, the work of the originators has evolved into differing versions, the Glaserian and Straussian iterations. The Straussian version (together with Corbin, 1998) is viewed by Glaser as a departure from the “true” grounded theory method, and is termed by him “full conceptual description”. His main critique is that Strauss’s method hinders emergence, and is instead, rather, “forcing” (Glaser, 1992). Glaser argues that in “full conceptual description” both data collection and interpretation are governed by a preconceived conceptual system which contradicts the actual idea of grounded theory as being inductive. The Straussian version has also been criticised for having rigid rules which are counterproductive to the spirit of creativity and the generation of grounded theory (Skodol Wilson & Hutchinson, 1996). In using grounded theory, I have used the works of Glaser as a guide (Glaser & Strauss, 1967; Glaser, 1978, 1992). The reason for this is that I found his inductive approach, with an emergent design and an attempt to stay open longer in analysis, to be more consistent with my intentions for this work and my view of qualitative methodology.

Content analysis
Content analysis is not one uniform method. It can be used with a quantitative approach or a qualitative approach, and can be applied to a variety of data with various depths of interpretation (Graneheim & Lundman, 2004). Traditionally, it has been described as a technique which allows objective, systematic, and quantitative descriptions of texts (Berelson, 1952), but it has evolved into a variety of different ways of analysing texts. Findahl and Höijer (1981) discuss interpretation in content analysis, referring to Dilthey (1922).
According to Dilthey, there are two ways to approach a text; from the outside and from the inside. The outside way is related to the effort of the natural sciences to explain, while the inside way is related to the effort of the human sciences to understand. The analysis can focus on the manifest content (the surface level, that which is literally present) or the latent content (the deeper underlying meaning) (Downe-Wamboldt, 1992; Kondrachi, Wellman & Amundson, 2002). Both cases involve interpretation, but the interpretations vary in depth and level of abstraction (Graneheim & Lundman, 2004). Findahl and Höijer (1981) also point out the relativity of interpretations in content analysis; the researcher is already making different judgements when registering the manifest content, as well as when creating the code scheme.

**MATERIAL AND METHODS**

The study informants were men and women with musculoskeletal symptoms (ache, pain, and/or discomfort) in the neck, shoulder, and/or back. Studies I and II focused on occupationally active people with musculoskeletal problems in the neck, shoulder, and/or back, while studies III and IV focused on people with chronic neck-shoulder problems. In this thesis, the term “non-specific neck-shoulder problems” is used, since people with a traumatic origin to their problems were excluded.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Main content</th>
<th>Informants</th>
<th>Setting</th>
<th>Methods/years of data collection</th>
<th>Analytical methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Experiences of illness and wellness</td>
<td>Ambulance personnel with musculoskeletal symptoms</td>
<td>One ambulance station</td>
<td>Narrative thematic interviews 2002–3</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>II</td>
<td>Experiences of illness and wellness</td>
<td>Nurses and nurses’ aides with musculoskeletal symptoms</td>
<td>Different patient ward units at three hospitals</td>
<td>Narrative thematic interviews 2004</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>III</td>
<td>Experiences of bodily illness</td>
<td>Informants from paper I+II, OR* nurses, and people with neck-shoulder problems</td>
<td>Different care settings, one massage clinic, recruitment via advertisement</td>
<td>Narrative thematic interviews 2002–5, Semi-structured interviews 2006</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>IV</td>
<td>Relationship between illness experiences and content of questionnaires</td>
<td>People with neck-shoulder problems</td>
<td>Recruitment via advertisement</td>
<td>Semi-structured interviews 2006 Questionnaires</td>
<td>Content analysis</td>
</tr>
</tbody>
</table>

* Operating room
Methods of data collection and procedure

Sampling and informants

The recruitment of informants in papers I-III was initially purposeful, and aimed at recruiting informants with varying illness experiences to provide useful, varied information, and thereafter theoretically driven, to enable further exploration of interesting findings (Coyne, 1997; Glaser, 1978). The sampling ended when saturation was perceived to be reached (Coyne, 1997; Glaser, 1978; Glaser & Strauss, 1967); that is, when the interviews became repetitive instead of enriching, the content of the categories was rich enough to give a full description, and the relationships between the categories were established. All informants included in the final data collection for paper III, and for paper IV were selected consecutively.

In paper I, 10 men working as ambulance personnel at a station located in a medium-sized city were recruited as informants. They all perceived musculoskeletal symptoms (ache, pain, or discomfort) in the neck-shoulder, upper back, and/or lower back. Initially, a purposive sampling was performed, from an epidemiological study focused on musculoskeletal symptoms among ambulance personnel (Aasa, Barnekow-Bergkvist, Ängquist & Brulin, 2005). Informants were chosen to give variation in musculoskeletal symptoms. Thereafter, a theoretical sampling was performed according to age and years of employment, to further explore the emerging process according to assumed differences related to age and experience.

In paper II, women were recruited from different acute care settings at three hospitals of different size. Eight female nurses and nurses’ aides with musculoskeletal symptoms (ache, pain, or discomfort) in the neck-shoulder, upper back, and/or lower back were involved. Initially, informants were purposefully selected from different ward units at different clinics at one hospital; thereafter, theoretical selection from two further hospitals of different size and location was applied, in order to further explore similarities and differences related to different workplaces. All informants in studies I and II were invited to participate via oral and written information supplied to their workplaces, after which they made contact to give their consent.

To further explore the experiences of bodily illness (III), renewed analyses were performed on data regarding bodily illness experiences from the interviews in study I-II, together with seven available interviews with operating room nurses. This was followed by four interviews with
men and women who had consulted a masseur at a massage practice in a small city in mid-
Sweden. To reach saturation, an additional 33 men and women with non-specific neck-
shoulder problems were interviewed. Paper IV involved 40 men and women with non-specific neck-shoulder problems. The informants with non-specific neck-shoulder problems in studies III and IV were recruited via advertisement placed in a local paper in a medium-sized town in the middle of Sweden. They were primarily recruited to a project studying sensorimotor functions in chronic neck pain. The subjects in that study were consecutively invited to participate in the present study, until 40 interviewees were obtained. Everyone who was asked to participate in the interview study agreed to be interviewed, except one. In study III, data from 33 of the interviews was estimated to be enough to reach saturation, while data for study IV was collected by also interviewing the remaining seven.

Table 2. Informants in the different studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Interviews</th>
<th>Informants</th>
<th>Occupation or occupational class</th>
<th>Age (min-max)</th>
<th>Normal activity/Partial or full sick leave or pre-term retirement (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>10</td>
<td>10 men</td>
<td>Ambulance personnel</td>
<td>28-52</td>
<td>10/0</td>
</tr>
<tr>
<td>II</td>
<td>8</td>
<td>8 women</td>
<td>Nurses, nurses’ aides</td>
<td>30-55</td>
<td>8/0</td>
</tr>
<tr>
<td>III</td>
<td>The above 18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>5 women</td>
<td>Operating room nurses</td>
<td>35-60</td>
<td>They all were working at least 50%</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>1 woman</td>
<td>2 blue-collar</td>
<td>22-63</td>
<td>4/0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 men</td>
<td>1 white-collar</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 retired</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>22 women</td>
<td>18 blue-collar</td>
<td>33-56</td>
<td>24/9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11 men</td>
<td>12 white-collar</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 self-employed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(total 62)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>40</td>
<td>25 women</td>
<td>21 blue-collar</td>
<td>27-56</td>
<td>31/9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15 men</td>
<td>15 white-collar</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 self-employed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Interviews**

Narrative thematic (I-III) and semi-structured interviews (III-IV) (Kvale, 1997; Sandelowski, 1991) were performed. An emergent design was employed in the narrative thematic interviews, with simultaneous data collection and analyses (see e.g. Glaser, 1978, 1992). After the preliminaries, the interviews started with asking the informant: “Tell me about how you perceive your health?” Thereafter the interviews gradually evolved to further explore
emerging topics of interest for the study. The interviews were narrative as well as reflective, as the aim was to obtain rich narratives about the interviewees’ experiences of wellness and illness in relation to their musculoskeletal disorders. The interviews lasted between 30 and 100 minutes and were tape-recorded and transcribed verbatim. In the semi-structured interviews (III-IV), use was made of an interview guide which had been developed on the basis of the results of previous interviews and analysis. The interview guide contained questions aimed at further exploring the course of MSDs (III) while at the same time gathering as full descriptions as possible of the symptom experiences that the informants had during this course (IV).

Choice of questionnaires

The choice of questionnaires for analysis in study IV was firstly based on an existing systematic review of work published between 1966 and 2000 regarding standard scales for measurement of functional outcome for cervical pain or dysfunction (Pietrobon et al., 2002). The following instruments were chosen: the Neck Disability Index (NDI) (Vernon & Mior, 1991), the Neck Pain and Disability Scale (NPDS) (Wheeler, Goolkasian, Baird & Darden, 1999; Goolkasian, Wheeler & Gretz, 2002), the Patient-Specific Functional Scale Self-Reports with Neck Dysfunction (PSFS) (Westaway, Stratford, Binkley, 1998), and the Northwick Park Neck Pain Questionnaire (NPQ) (Leak et al., 1994). Scales that only presented items concerning disability or dysfunction were excluded.

Secondly, a complementary search for articles describing relevant instruments which were published between 2000 and March 2007 was performed on the PubMed database using the keywords: neck pain scale; neck pain and outcome measures; neck pain and questionnaire. The following scales were found and added to the analysis: the Bournemouth Questionnaire (BQ) (Bolton & Humphreys, 2002), the Cervical Spine Outcome Questionnaire (CSOQ) (BenDebba, Heller, Ducker & Eisinger, 2002), the Core Neck Pain Questionnaire (CNPQ) (White, Lewith & Prescott, 2004), and the Extended Aberdeen Back Pain Scale (EABPS) (neck, shoulder, low back) (Williams, Wilkinson & Russell, 2001).

A newly-constructed questionnaire was also added to the sample; The Profile Fitness Mapping questionnaire (PFM) (Björklund, Hamberg, Heiden & Barnekov-Bergkvist, in preparation). The value of this final questionnaire was that it was developed using the
experiences of people affected by chronic neck-shoulder problems. Thus, in all, nine questionnaires were included in the analysis.

**Analytical methods**

**Grounded theory**
To begin the analysis (I-III), the text was read several times and meaning units were identified. The next step was a condensation of the meaning units in order to clarify the meaning of the content, whereupon the meaning units were labelled with descriptive codes. Thereafter, the codes were thematically grouped into categories, and comparisons were made within and between the categories. Throughout the process of interviewing and analysis, notes (memos) were written to capture the thoughts and ideas that emerged, and figures were drawn to illuminate these ideas. Constant comparison was made between new and old findings, emerging ideas, the categories, and the underlying text; and newly arising questions were further elaborated in the following interviews. As the properties and dimensions of the categories were established, as well as the relationships between the different categories, a core category emerged and a tentative theory was developed. Data collection ended when saturation was reached; that is, when the interviews produced repeated information instead of new, and there was a possibility of describing the emerging categories, establishing the relations between the categories, and elaborating on the model. The literature review was partly made as a concurrent process to this analysis.

**Content analysis**
The content analysis (IV) was performed in three steps; analysis of interviews, analysis of questionnaires, and comparison of the results to find similarities and differencies. The analysis of the interviews was performed using content analysis (e.g. Graneheim & Lundman, 2004) on the manifest content of the interviews. The interviews were read one by one, and all symptom descriptions that the informants related to their musculoskeletal problems were marked. A list of all specific symptoms was created, and the interviews were re-read to check that nothing was missing from the symptom list. Thereafter, the symptoms (codes) on the symptom list were arranged into subcategories according to content, which in turn were arranged into categories and main categories. The categorisation was discussed and agreed upon within the research group as well as with external specialists. As a last step, the occurrence of each code in the interviews was checked, and frequencies were calculated for the different codes.
Next, the chosen nine instruments were analysed. As a first step, the articles presenting the development of the different instruments were reviewed for data on developmental background and choice of included items. In the content analysis of the questionnaires, all items related to pain and other symptoms included in the instruments were listed and sorted into different categories, according to content. Items concerning disability or dysfunction irrespective of pain were excluded. Various aspects of each instrument’s ability to measure fluctuations of symptoms (as different time perspective and intensity measures) were also considered in the analysis.

Finally, the results of the first two analyses were compared for similarities and differences between the symptoms described by the affected and the symptoms included in the questionnaires.

**Ethical considerations**

The illumination of health experiences from the perspective of those affected can make a useful contribution to facilitate effective prevention and treatment. Several studies (e.g. Hutchinson, Wilson & Skodol Wilson, 1994; Payne et al. 1996) have shown that people enjoy participating in interviews; as they often consider it to be a positive experience, and feel motivated by the knowledge that others can benefit from their experiences. This was also our experience throughout this study. In gathering, analysing, and presenting the material, we were guided by the goal of taking part in, interpreting, and presenting the informants’ experiences in a respectful way. Participation was of course voluntary, as was the choice of what to talk about and how much to elaborate on the story. The informants were also able to choose the time and place of the interview. Tapes, transcripts, and presentation of results was handled in such a way that no one except the interviewer had access to, or could identify, any individual data.
FINDINGS

Health experiences of occupationally active people with MSDs

Studies I and II present the health experiences of men (ambulance personnel) and women (health care personnel) who suffered from musculoskeletal disorders but were still active in working life. The analysis revealed a process of striving for balance between experiences of illness and wellness (Fig 2). The informants’ health experiences were not a state of either wellness or illness, but of both, in varying degrees at different times. The process of striving for balance started when the illness experiences became too intrusive, and was a process of both minimising the impact of illness by accepting and handling it, and attaining and maintaining enough wellness to strike a balance. The state of balance was the experience of feeling “well enough”.

For both men and women, illness was characterised by disembodiment, vulnerability, and exhaustion. The illness experiences incorporated feelings of the previously silent body making itself heard, of being vulnerable when suffering came too close, and of becoming worn out. In their experiences of vulnerability, the men also stressed the risk of becoming hardened. The illness experiences were counterbalanced by wellness, where some differences
could be recognised between the men and the women of this study. The women experienced their wellness as being nurtured by experiences of relatedness, usefulness, and existential enjoyment, while wellness among the ambulance men was nurtured by experiences of personal acknowledgement, the great affinity of the group, and by experiences of excitement, challenge, and freedom (Table 3).

<table>
<thead>
<tr>
<th>Core cat.</th>
<th>Category</th>
<th>Subcategory</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Striving for balance</td>
<td>Encountering illness as an experience and a threat</td>
<td>The body makes itself heard</td>
<td>The body makes itself heard</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One can get worn out</td>
<td>One can get worn out</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One can become too vulnerable or hardened</td>
<td>Being vulnerable when suffering gets too close</td>
</tr>
<tr>
<td></td>
<td>Attaining and maintaining wellness through nurturing</td>
<td>Getting excitement and being challenged</td>
<td>Feeling related</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Having freedom and flexibility</td>
<td>Feeling useful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being “someone” and making a difference</td>
<td>Being able to enjoy existence.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being one of the gang</td>
<td></td>
</tr>
<tr>
<td>Accepting and handling illness</td>
<td>Performing inner reasoning to reach acceptance</td>
<td>Accepting illness as an experience in daily life</td>
<td>Searching for arguments to reject illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accepting illness as a threat in daily life</td>
<td>Searching for arguments to accept illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accepting illness as an inevitable part of the future</td>
<td></td>
</tr>
<tr>
<td>Handling illness as an experience and a threat</td>
<td>Preparing oneself</td>
<td>Protecting and caring for the body</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Handling the situation</td>
<td>Suppressing, adapting or leaving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Keeping the lid on vs. getting relief</td>
<td>Finding strength and/or shielding</td>
</tr>
</tbody>
</table>

In the balancing process, the element of accepting and handling illness appeared to be vital for attaining and maintaining wellness. Among the ambulance men (I), the process of accepting and handling illness consisted of two parts or stages. In order to be able to handle their illness, the men were forced to accept it, but acceptance was also the final option when they found no other way of handling it. The inner reasoning on the path to acceptance consisted of descriptions of the conditions that made the illness experience acceptable. There was an inner reasoning of acceptance of illness from different perspectives: accepting illness as an experience in daily life, accepting illness as a threat in daily life, and accepting illness as an inevitable part of the future. To reduce the experienced and/or threatening illness, the ambulance men were handling illness as an experience and a threat, which was achieved by preparing oneself, handling the situation, and keeping the lid on vs. getting relief.

The process of inner reasoning described by the female health care personnel (II) initially started with an attempt to reject illness, trying to ignore it when it appeared. As the experience became more intrusive, the reasoning turned to arguing the aspects that made illness
acceptable, which was followed by different attempts to handle the illness by preventing its occurrence and handling its consequences. The interviewed women inwardly reasoned their way towards acceptance by searching for arguments to reject illness and searching for arguments to accept illness. There were different ways of handling illness, depending on whether the experience was of becoming worn out, of becoming too vulnerable, or of the body making itself heard. Handling illness was performed by suppressing, adapting or leaving; finding strength and/or shielding; and protecting and caring for the body.

The reasoning of the ambulance men (I) seemed to be oriented towards acceptance, as acceptance made it possible to remain at work, which in turn was highly valued as their wellness was mainly related to work. Illness was also seen as a natural part of ambulance work. The reasoning of the female health care personnel (II) began with a search for arguments to reject illness, and attempts to ignore it when it appeared. Illness was not acceptable, as it was necessary to be fit, and to take one’s share of the burden. As the illness experience became too intrusive, the reasoning turned to arguing the aspects that made illness acceptable. To reduce the experienced and/or threatening illness, the informants handled illness as an experience and as a threat. Among the ambulance men (I), handling illness seemed to have a clear temporal dimension, regardless of the illness dimension that was being handled, as the men were preparing before, handling during, and getting relief afterwards. Among the female health care personnel, handling illness seemed to be related to what illness dimension was handled, and performed in the present.

The disease course of neck-shoulder disorders

Study III further explores the experience of bodily illness, this time focusing on men and women with chronic musculoskeletal disorders in the neck-shoulder region. The findings give new insight into the process of developing neck-shoulder disorders. The course of the disorder was described as a process characterised by uncontrollable fluctuations (Fig. 3). The process usually developed from a beginning with insidious symptoms to a state of constant discomfort. The participants experienced calmer periods during the course, but intermittent events of increasing illness were always lying in wait. Periodic moments of consuming intensity made the condition hard to endure. A spectrum of different symptoms was described along the line of this fluctuating process.
The majority of the informants were not aware of the exact point in time when their musculoskeletal symptoms had started. They most often talked about them as insidious symptoms and described them as being diffuse. These symptoms included fatigue (muscular as well as general), stiffness, tenderness, and a slight dull ache in the neck and/or shoulder region, which gradually worsened, spread, and appeared more and more often. Occasional headache and wryneck were also mentioned in some cases. A few informants instead presented the appearance of their symptoms as an isolated case of sudden pain, often taking the form of a strong and painful wryneck. The combination of a diffuse beginning but a noticeable first occurrence of symptoms was also described.

Most of the informants presented experiences of calmer periods, which despite being “calmer” were characterised by constant bodily illness. The calmer periods could be experienced as fairly manageable, although some symptoms were present all the time, such as stiffness, tenderness, and pressure in the neck-shoulder region. Other symptoms which were sometimes present were aching and crunching, creaking, or cracking in the neck. Difficulties in bending the neck and turning the head were also common. After the informants had lived with their symptoms for several years, they could experience them as an everyday thing, as they had got used to them.

Figure 3. The course of neck-shoulder disorders

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The calmer periods were interrupted by intermittent events of increasing illness, which could occur at any time or on certain occasions. When the impairment was experienced as occurring at any time, it came on with no warning, without the individual being aware of having done anything special that could trigger the symptoms. More often, the impairment occurred on certain occasions, sometimes depending on different things that the person had done. Increased strain, whether physical load or mental stress, could trigger the symptoms, as could overly-long periods spent in certain physical postures, such as walking, standing, sitting, and even lying. Bending the neck forward or backward, turning the head, and working with hands/arms above shoulder height could also trigger impairment. The informants experienced a need to adjust their movements and activities in order to avoid triggering impairment, as impairment was always “lying in wait.” They were constantly striving to adjust to make their situation more acceptable. During periods of impairment, the symptoms could be experienced as remaining constant over time, as remaining the same but with some variation, or as changing over time. The variation could be in the spread of aching and numbness, the intensity, or the pain threshold. The symptoms could change; spread, move, become more and more intense, and/or deepen. One way that the symptoms could manifest was as increasing stiffness and pressure in the neck-shoulder region, and an ache that increased in intensity and spread to the head, shoulder blades, and arms. The sensation of the intensified pain was described as burning, stinging, and increasing pressure.

During the disease course, “worst moments” were described by the informants, with an intensity that was sometimes consuming. The most severe symptoms included a great deal of muscular tension, pain that was described as pulsating or throbbing, and an intense pressuring ache. This intense ache could cover the entire neck-shoulder region, from the shoulders and shoulder blades up into the head. Sometimes, radiating pain and swelling of the arms and hands was described as part of the picture, as well as pain in the facial region, jaws, and ears. As the pain became really intense, other bodily and mental functions were also affected. In these cases, a feeling of general sickness was described, as if the whole body was engaged, with symptoms such as general tiredness and feebleness, dizziness, nausea, oversensitivity to sound and light, a runny nose, hoarseness, and irritated eyes. The intense symptoms had negative effects on mood and on the ability to concentrate and think clearly. The moments of consuming intensity also severely affected the participants’ social lives, as it was impossible to think of anything else, and their only desire was to be alone.
The correspondence between symptoms and questionnaires

The comparison between the symptoms narrated by people with chronic neck-shoulder disorders and the content of neck-shoulder questionnaires for assessing pain and other symptoms showed both similarities and differences.

- A variety of symptoms were experienced.

The narrated experiences of neck-shoulder symptoms revealed bodily, mental/cognitive, and emotional engagement, and included more general and more severe symptoms than are usually related to musculoskeletal disorders (Table 4).

Bodily engagement included the neck, shoulder, and shoulder blades, but also the rest of the body. The symptoms could be divided into experiences of functional impairment and pain experiences. The functional symptoms were characterised by tenseness and stiffness (neck, shoulder, shoulder blades), but also as tiredness (neck, shoulder) and powerlessness, and as locking and wryneck (neck). The pain experiences were described as tenderness, gnawing, smarting, burning, and stinging (neck, shoulder, shoulder blades), as pressure and pressuring ache (neck, shoulder), and as cutting, pricking, pulsating, pounding, and throbbing (neck). For the rest of the body, experiences of pain spread as pain and/or numbness in arms, as headache, and as aching and stiffness in the jaws were described. The interviewees also expressed experiences of a general engagement of the rest of the body, involving dizziness, nausea and vomiting, and feeling feeble and out of sorts. Less common symptoms were presented as irritated, tired, or runny eyes with blurry vision, and hoarseness, pain and cramp in the larynx. The interviewees also described a mental engagement associated with their musculoskeletal problems. This was experienced as fatigue, difficulties in concentrating, and sensitivity to sound and/or light. Finally, the emotional engagement manifested as irritation, irritability, and sadness or depression.

- Few questionnaires are developed using the experiences of people with neck-shoulder disorders.

The analysis of the questionnaires for assessing pain and other symptoms revealed that the majority had been developed on the basis of theories of musculoskeletal symptoms; only two questionnaires had been developed on the basis of the experiences of those affected. One, the Profile Fitness Mapping questionnaire (PFM), was developed using the illness experiences of
20 patients with neck problems to decide which items to include. The other one, the Extended Aberdeen Back Pain Scale (EABPS), had asked for patient views on the questionnaire. A third questionnaire, the Patient-Specific Functional Scale (PSFS) that allows the respondents to generate a list of three items when answering the questionnaire, involved patient experiences, but the development of the questionnaire was not based on the experiences of those affected.

- Most questionnaires include only a few symptoms.

Taken as a whole, the questionnaires covered many of the symptoms mentioned in the interviews. However, each individual questionnaire only included a few symptoms. Beside neck-shoulder pain, other important symptoms may be categorised as follows: other neck symptoms, spread of pain and other symptoms, other symptoms, mental/cognitive engagement, and emotional engagement. None of the questionnaires covered all of the symptoms included in this categorisation. PFM included 15 different symptoms; CSOQ ten; NPDS six; BQ five; EABPS and NDI four; CNPQ and NPQ three (Table 5).

- The nuances of symptoms are rarely considered.

Only NPDS and PFM took quality of pain or other neck-shoulder symptoms into consideration; as neck stiffness in NPDS, and as soreness, stiffness, tension, cracking, tiredness, weakness, and locking in PFM. None of the reviewed questionnaires differentiated the qualities of the neck pain. However, some did consider different qualities of shoulder and/or arm symptoms, as pins and needles in the arms (NPQ), weakness or tingling in the arms or hands (CSOQ), or loss of feeling, weakness (EABPS), and numbness (PFM) (Table 5).

- The fluctuations of symptoms are not usually taken into consideration.

Pain intensity was measured in all questionnaires; otherwise, the included aspects of pain differed between the questionnaires (Table 6). Pain related to different activities was the most commonly occurring. The questionnaires which included other aspects of variation in symptoms asked for pain at the moment (CSOQ, NDI, NPDS, NPQ), at its worst (CSOQ, NPDS), at its best (CSOQ), or over the last 24 hours/since the last measurement (NPQ). NPQ also asked about continuous versus intermittent symptoms.
Table 4. Categorisation and frequency of occurrence of symptoms of the interviewees (n=40)

<table>
<thead>
<tr>
<th>Main category</th>
<th>Category</th>
<th>Subcategory</th>
<th>Symptom *</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neck</td>
<td>Function</td>
<td>Tenseness, stiffness</td>
<td>1</td>
<td>34</td>
<td>85</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Creaking, cracking</td>
<td>2</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Weakness, tiredness, powerlessness</td>
<td>3,4</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Locking, wryneck</td>
<td>5</td>
<td>14</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>Tenderness</td>
<td>-</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gnawing, smarting</td>
<td>-</td>
<td>16</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burning, stinging</td>
<td>-</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Shoulder blade</td>
<td>Function</td>
<td>Tenderness</td>
<td>-</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gnawing, smarting</td>
<td>-</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burning, stinging</td>
<td>-</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pressure, pressuring ache</td>
<td>-</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unspecified ache/pain</td>
<td>x</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Rest of the body</td>
<td>Function</td>
<td>Tenseness, stiffness</td>
<td>-</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tenderness</td>
<td>-</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burning, stinging</td>
<td>-</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unspecified ache/pain</td>
<td>x</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>Pain, numbness in arms</td>
<td>7</td>
<td>18</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Headache</td>
<td>8</td>
<td>22</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ache, stiffness in jaw</td>
<td>9</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Pain spread</td>
<td>Eyes; irritated, runny, tired, blurred vision</td>
<td>-</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Throat; hoarseness, pain, cramps in larynx</td>
<td>13</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dizziness</td>
<td>12</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nausea, Vomiting</td>
<td>10</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cold symptoms, snottiness, feebleness, feeling out of sorts</td>
<td>10</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Mental engagement</td>
<td>Fatigue</td>
<td>11</td>
<td>9</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty concentrating</td>
<td>14</td>
<td>10</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sensitivity to sound/light</td>
<td>15</td>
<td>3</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Burnout)</td>
<td>8</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional engagement</td>
<td>Irritation, irritability</td>
<td>17</td>
<td>18</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sadness, depression</td>
<td>16</td>
<td>6</td>
<td>15</td>
</tr>
</tbody>
</table>

*Numbers after symptoms — see corresponding numbers in table 5. (x= unspecified symptoms which are present in both table 4 and 5.)
Table 5. Items assessing pain and other symptoms included in the questionnaires

<table>
<thead>
<tr>
<th>Symptom area</th>
<th>Symptom</th>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neck</td>
<td>Pain</td>
<td>BQ, NDI, NPDS, NPQ, PFM</td>
</tr>
<tr>
<td>Neck-shoulder</td>
<td>Pain</td>
<td>CNPQ, CSOQ, EABPS</td>
</tr>
<tr>
<td>Other neck symptoms</td>
<td>Stiffness</td>
<td>NPDS, PFM</td>
</tr>
<tr>
<td></td>
<td>Tension, cracking, tiredness, weakness, locking</td>
<td>2-6</td>
</tr>
<tr>
<td>Spread of pain and other symptoms</td>
<td>Symptoms in arm/hand</td>
<td>CNPQ, CSOQ, EABPS, NPQ, PFM</td>
</tr>
<tr>
<td></td>
<td>Headache</td>
<td>CSOQ, EABPS, NDI</td>
</tr>
<tr>
<td></td>
<td>Jaw trouble</td>
<td>PFM</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>Sleeping difficulties</td>
<td>EABPS, NDI, NPDS, NPQ, PFM, CSOQ</td>
</tr>
<tr>
<td></td>
<td>Feeling sickly /unwell/indisposed</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Feeling low in energy/sluggish</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Dizziness or balance disturbance</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Difficulty swallowing</td>
<td>CSOQ, PFM</td>
</tr>
<tr>
<td></td>
<td>Difficulty breathing</td>
<td>-</td>
</tr>
<tr>
<td>Mental engagement</td>
<td>Difficulty concentrating /thinking clearly</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Sensitivity to light/sound</td>
<td>15</td>
</tr>
<tr>
<td>Emotional engagement</td>
<td>Affected emotions</td>
<td>NPDS</td>
</tr>
<tr>
<td></td>
<td>Depression, hopelessness</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Anxiety, tenseness</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Irritability, short temper</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Worry about physical health</td>
<td>-</td>
</tr>
</tbody>
</table>

* Numbers after symptoms — see corresponding numbers in table 4. (x= unspecified symptoms which are present in both table 4 and 5.)

Table 6. Different aspects of pain addressed by the questionnaires.

<table>
<thead>
<tr>
<th>Pain aspect</th>
<th>Intensity</th>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Duration (How many days in pain over the last 2 weeks?)</td>
<td>EABPS</td>
</tr>
<tr>
<td></td>
<td>Variation and duration (continuous vs. intermittent symptoms, combined with duration)</td>
<td>NPQ</td>
</tr>
<tr>
<td></td>
<td>Intensity/frequency (How often? How much?)</td>
<td>PFM</td>
</tr>
<tr>
<td></td>
<td>At its worst</td>
<td>NPDS, CSOQ</td>
</tr>
<tr>
<td></td>
<td>At its best</td>
<td>CSOQ</td>
</tr>
<tr>
<td>Temporal aspects of pain</td>
<td>At the moment</td>
<td>NDI, NPQ, NPQ, CSOQ</td>
</tr>
<tr>
<td></td>
<td>Over the last 24 hours</td>
<td>PSFS, NPQ</td>
</tr>
<tr>
<td></td>
<td>Over the last 1-2 weeks</td>
<td>BQ, CNPQ, EABPS</td>
</tr>
<tr>
<td></td>
<td>Compared to latest measurement</td>
<td>NPQ</td>
</tr>
<tr>
<td>Other aspects of pain</td>
<td>Pain related to different sorts of activity</td>
<td>BQ, CSOQ, EABPS, NDI, NPDS, PFM</td>
</tr>
<tr>
<td></td>
<td>Pain related to rest</td>
<td>CSOQ, PFM</td>
</tr>
</tbody>
</table>
The correspondence between individual questionnaires and the experiences of those affected is usually low. When all items included in all questionnaires were taken together, many of the symptoms described in the interviews were covered. However, when comparisons were made with each of the different questionnaires, the correspondence in most cases was low. Most questionnaires cover only a minority of the symptoms described by people with neck-shoulder problems.

The following comparisons relate to tables 4 and 5, where the numbers after each symptom correspond to the occurrence of that symptom in the other table.

The questionnaires covered all functional symptoms from the neck presented in the interviews, but none of the qualitative differentiation of pain. The functional symptoms from the shoulder presented in the interviews might have been considered in the questionnaires as tenseness, stiffness, and tiredness, but it was not specified as belonging to the shoulder. The differentiated pain experiences included in the interviews were not present in the questionnaires. The interviews included descriptions of some functional and pain symptoms from the shoulder blade region, while no such symptoms were included in the questionnaires. For the rest of the body, experiences of pain spread were present in both interviews and questionnaires. Symptoms interpreted as general engagement of the body were presented in the interviews, corresponding to feeling sickly/unwell/indisposed in the questionnaires. Eye symptoms were described by a few of the interviewees, but were not present at all in the questionnaires. Mental engagement and emotional engagement were present in both interviews and questionnaires. Once again, it should be noted that these comparisons include the questionnaires as a group, and not individually. No questionnaire covered all experiences from the interviews. PFM was found to be the most comprehensive of the questionnaires.

- Mental and emotional engagement is often overlooked. Some symptoms were only considered in only a few of the questionnaires (Table 5). Prominent among these were mental/cognitive symptoms, along with some of the symptoms of emotional engagement described in the interviews. Symptoms from the shoulder blades were not covered by any of the questionnaires. Sleeping difficulties was included in several questionnaires (Table 5), but it was not included in the categorisation of illness experiences presented in the interviews (Table 4), since it was not interpreted as a symptom per se, as the
informants attributed their sleeping difficulties to their pain and other symptoms. Breathing difficulties was included in one of the questionnaires (PFM), but were not present in the interviews.

DISCUSSION

The findings in this thesis show that the occupationally active men and women with MSDs were “striving for balance” (I-II), that the disease course of chronic neck-shoulder disorders is characterised by “uncontrollable fluctuations” (III), and that most neck-shoulder questionnaires have a low correspondence to the variety of symptoms experienced during this course (IV).

Striving for balance

Balancing

The balancing process (I-II) started when illness became too intrusive. It was a process of minimising the impact of illness by accepting and handling it, while attaining and maintaining wellness to feel well enough. When striving for balance, the interviewees kept on working to continue being nurtured at the same time as they made different efforts directed at minimising the impact of their illness.

Studies on health or health care using the concepts of balance and balancing have been conceptualised into three types of studies according to focus (Thulesius, Håkansson & Petersson, 2003). In studies on illness and disease, balancing has been characterised as normalising and surviving. It has been recognised to have properties of weighing, shifting, and compensating. Balance between illness and wellness has also been termed as balance-seeking fluctuations (Adams et al., 2000), as a dialectic relationship (Jensen & Allen, 1993), and as a shift in perspectives (Paterson, 2001). All these descriptions share some similarities with the findings of the first two studies of this thesis; there was a dialectic relation between illness and wellness, as the interviewees described fluctuations in their health experiences, and they shifted between focusing on illness and on wellness, trying to keep on living as normally as possible.

Balance is well recognised as an important concept related to chronic illness. The term “balancing” has been used to describe, for example, experiences of myocardial infarction (Kristofferzon, Löfmark & Carlsson, 2007), diabetes (Paterson, Thorne & Dewis, 1998),
chronic kidney disease, and schizophrenia (Beanlands, McCay & Landeen, 2007). The concept of balancing in these studies has much in common with the process of balancing in this thesis, since they also depict people as being active in the process, and include aspects of accepting and handling. Processes in chronic illness have previously also been described in terms of transitions (Chick & Meleis, 1986; Kralik, 2002) and trajectory (Corbin & Strauss, 1991; Granger, Moser, Germino, Harrell & Ekman, 2006). In comparison to transition and trajectory, it seems that balancing illuminates a more flexible, continuously shifting experience which involves an acting person, instead of a predictable trajectory through different stages (cf. Paterson, 2001).

**Focusing wellness**

The physical aspect of wellness was notably missing from the narratives in the present work. Wellness was depicted in relation to self as a social being, which was nurtured in interaction with others. The informants were focused on the possibility of continuing in their employment, rather than taking sick leave or assuming the role of a sick person, as work was important to them as a part of their identities and their social life, as well as being their means of making a living. They were therefore ready to accept a considerable degree of illness, as work was the priority. Through work, the interviewees felt related to and useful, and their desired identities were confirmed, indicating that work contributed to the nurturing of wellness. However, at the same time, their bodies made themselves heard, they felt vulnerable and they felt worn out.

The acknowledgement of others as being one of the gang, as well as the feeling of being “someone” and making a difference, also nurtured the men. For the women, the nurturing sources included feeling useful in their identities as nurses, as well as feeling related to colleagues, friends, and family. High-quality social relations have been discussed as being central to human health (Ryff & Singer, 1998). It has been argued that feeling related to others (Moch, 1998), along with the perception of receiving and providing valued support (Adams et al., 1997), increases the meaningfulness of life and wellness in general. Identity has also been found to be an essential element in promoting wellbeing and life satisfaction, as life meaning is derived in the context of identity (Christiansen, 1999). Identity and self-esteem are built upon the acknowledgement or attention we get from others, and on our personal expectations (Barbalet, 1999; Goffman, 2000). In the present study, we found that excitement, challenge, and freedom/flexibility were important for the self-esteem of the ambulance men,
as they were nurtured in accordance with their personal expectations. Others have also described keeping a positive sense of self as being important in balancing (Beanlands et al., 2007; Paterson, 2001). Paterson et al. (1998) concluded that people with diabetes focus on wellness instead of illness in their attempt to achieve balance. They do this as an attempt to create consonance between self-identity and the identity created by the disease, by the constructions of the illness by others, and by life events (Fife, 1994). With “wellness in the foreground” (Paterson, 2001), the self, not the diseased body, becomes the source of identity. Shifting to a wellness focus allows people with chronic illness a means to mediate the effects of the disease. Paterson’s model enhances our understanding of why people with musculoskeletal problems strive to keep on working.

Aspects of gender can contribute to the understanding of health experiences, via the awareness that different societies with their different groups and cultures can influence the shaping of bodies, health, disease, and illness, and the ways in which these things are experienced (e.g. Courtenay, 2000; Courtenay & Keeling, 2002; Freund et al., 2003). Part of this is that imbued dominant norms of femininity and masculinity encourage people to conform to stereotypic beliefs and behaviours (e.g. Bohan, 1993). Connell (1995) describes hegemonic masculinity as the idealised form of masculinity at a given place and time. The “tough ambulance man” can be seen as one example of hegemonic masculinity. In performing their desired identities, in being one of the gang, the men conform to such beliefs and behaviours. Excitement, challenge, freedom and flexibility, being someone, and making a difference are all related to the hegemonic masculinity of this particular place and time (cf. Connell, 1995). The health experiences expressed by the female health care personnel can be interpreted in terms of the corresponding dominant “good nurse” norm of femininity. Inherent in the role of the good nurse are expectations of being able to provide high-quality care, to take one’s share of the burden, and to be the healthy provider. Despite the working conditions and their own health experiences, the female health care personnel conformed to those expectations, since all these things contributed to wellness. By doing this, (doing gender, cf. West and Zimmerman, 1987), there might also be a risk of neglecting symptoms which thereby can become chronic.

**Intrusive illness**

For both men and women, the illness experience had three dimensions; bodily illness, vulnerability, and exhaustion. The previously silent body now insisted on attention (Leder,
in a process ranging from a merely temporary or mild sensation to something that was always present and that had increasingly become more unbearable. The informants also felt vulnerability in their work, in encountering the patients’ needs and suffering. Their experiences of exhaustion were mostly related to rapid organisational change, continuous budget cuts, and feelings of being unable to influence the process. For the ambulance men, the greatest source of emotional exhaustion was the heightened educational requirement, with the resulting split in the group and changes in status, roles, and work tasks. The health care personnel expressed feelings of inadequacy regarding the patients, as they lacked time to properly care for their needs. At the same time, the continuous reorganisation changed the structure of the work groups and affected cooperation, relationships, and the work climate.

The illness experiences were described in terms of embodiment and disembodiment. When talking about their bodily illness, the informants expressed experiences of disembodiment, a separation between the self and the body, as the latter became apparent, as described by Leder (1990). They usually referred to the body as “it”, as something that was unreliable; something that was hurting them, and letting them down. The other illness experiences, of becoming worn out and being too vulnerable, were instead described as embodied (embodied thoughts) (Rosaldo, 1984). The informants often used bodily expressions to describe these illness experiences; for example, becoming worn out was described as “the body has taken a beating”, and “it’s hard to get it out of the body”. When describing vulnerability and its different properties, the ambulance men used metaphors such as the body as a container, and emotions as fluid or gas, a phenomenon previously described by Lupton (1998).

**Handling illness**

The rejection and acceptance in handling illness described in studies I and II could be compared to a negotiation with oneself (Kristofferzon et al., 2007) and approaching illness (Beanlands et al., 2007). Handling illness, in turn, could be compared to accommodating and connecting (Beanlands et al., 2007), and to making one’s own decisions and acting for oneself (Kristofferzon et al., 2007). Paterson et al. (1998) describe how people with diabetes try to assume control by learning to know their bodies, by learning to manage their diabetes, and by fostering supportive relationships. People with myocardial infarction are described as struggling for control by negotiating with themselves, by relying on their own capabilities, by changing their attitude, and by making their own decisions and acting for themselves (Kristofferzon et al., 2007). People with chronic kidney disease and schizophrenia have been
described to approach their illness, to accommodate, and to connect (Beanlands et al., 2007). The men and women with MSDs handled their illness in different ways. For the ambulance men, this handling had a clear temporal dimension, as they were preparing before, handling during, and getting relief after strain and illness. This temporal differentiation was not present in the stories of the women, as they handled their illness as and when it appeared.

The interaction in health care involves different social roles for the healthy carer and the sick patient (cf. Parsons, 1979). To experience illness (e.g. musculoskeletal problems) at the same time as being the healthy carer (the tough ambulance man or the good nurse) may contribute to a role conflict. There may also be problems linked to accepting and showing the symptoms and problems associated with the disorder, as these are signs and symbols belonging to the role of the sick. When health care personnel become sick, they still have to stick to their roles as healthy carers and continue to show the official feelings (cf. Collins, 2004; Hochschild, 2003), as otherwise a disturbance in their roles may become visible which would influence their ability to nurture wellness. This was evident among the women, in their initial rejection of illness, and it has also been described in other studies on health care professionals with MSDs (Cromie, Robertson & Best, 2002). If it is hard to accept and show bodily illness, it can also be hard to avoid and to cure it. On the other hand, accepting illness as normal, as the ambulance men did, also has negative effects on avoidance and cure.

Working in health care includes meeting sick people’s needs in different ways, which can be seen as emotional work (cf. Hochschild, 2003). By showing certain feelings, the health care personnel and the ambulance men mediate other feelings to the patients (e.g. security, trust, confidence, hope). These are “official” feelings, those required to perform their task properly. The work of the health care personnel and the ambulance men in turn evokes feelings in those performing the work (such as vulnerability in caring for the sick and dying — private emotions) which are not always suitable for the official role. It is only legitimate to show and handle these private emotions in the privacy of the work group or at home. It can be difficult to accept and show vulnerability while maintaining the role of the “tough ambulance man” or the “good nurse”. However, in the ambulance service, the formal and informal briefing system was perceived to reduce this vulnerability, while informal support from colleagues was important in health care.
Masculinities and femininities are not fixed, but are constantly changing in an ongoing reconstruction (Courtenay, 2000). In our material, this was clear in the men’s changing approach to handling vulnerability. The “old foxes” “kept the lid on things”, while their younger colleagues were “releasing the pressure”, and “letting off steam”. The “rookies” initially adopted the beliefs and behaviours of the “old foxes”, before adjusting to those of the younger, but still experienced, men. Their stories bore evidence of a hegemonic masculinity (Connell, 1995) that was changing over time, as well as conforming to the dominant norms and changing pre-held conceptions on joining the group. Among the female health care personnel, the reconstruction of femininities was not so obvious.

Can handling emotions have effects on health? Empirical studies have reported a relationship between psychological and physical strain and MSDs, among health care personnel as well as other occupational groups (e.g. Bongers et al., 2006; Gonge et al., 2002). The possibility to reduce health risks by reducing psychological strain is also known in relation to other conditions, as interventions directed at balancing demand, control, and support have been shown to have effects on both feelings (experiences of work) and physiological measures (lipoprotein levels) (Orth-Gomér, Eriksson, Moser, Theorell & Fredlund, 1994). If considering psychological strain, and demand, control, support, as emotions or related to emotions, the following conclusion might be drawn: Emotions can have negative physical consequences. Balancing emotions to get lowered negative/heightened positive emotions can decrease the negative physical consequences.

As illness and wellness exist in a constant balancing process, wellness should also be considered as a health-promoting factor, especially given the argument that positive emotions might undo the effects of negative emotions, are incompatible with negative emotions, and can trigger upward spirals towards improved emotional well-being (Fredrickson, 2001). The effects in the case of MSDs could be lowered muscle tension and the avoidance of negative physiological response in the muscles, and thereby the prevention or relief of problems, in parallel to an increased wellness experience. If accepting this reasoning, it might be useful to consider emotions related to musculoskeletal disorders in health promotion, prevention, and rehabilitation.
Uncontrollable fluctuations

In study III, the course of the neck-shoulder disorders is described as a process characterised by uncontrollable fluctuations. The process usually developed from a beginning with insidious symptoms, to a state of constant discomfort. The participants experienced calmer periods during the course, but intermittent events of increasing illness were always lying in wait. Periodic moments of consuming intensity made the condition hard to endure.

The disease course of neck-shoulder disorders has not previously been described in detail using the experiences of the informants. Kuorinka and Forcier (1995) related the disease course of MSDs to the classic two-step process (prepathogenesis and pathogenesis) of the “natural history of any disease of man” described by Leavell and Clark (1965). Recent studies have aimed to examine or describe the natural, individual, and clinical course of neck-shoulder disorders (Aublet-Cuvelier et al., 2006; Bot et al., 2005; Pernold et al., 2005); however, their data was gathered via questionnaires or clinical examinations.

The disease course of MSDs is described by Kuorinka and Forcier (1995) as beginning with fatigue and discomfort after strenuous exercise. The symptoms are described as being persistent under certain conditions. The temporal length of each phase is unknown, and a disease state may develop in hours, days, weeks, or months. The authors concluded that the current knowledge of MSDs was insufficient to allow a general description of the course of such conditions. The disease course presented in the present study is in line with the conventional assumptions described by Kuorinka and Forcier (1995), but our findings reveal greater fluctuations in the process. The disease course of chronic neck-shoulder disorders presented in study III is described as consisting of a baseline of symptoms, which go from unnoticeable to constant discomfort, in addition to symptom peaks along this baseline. This is in agreement with more recent discussions of the disease course as having a great variability, including recurring symptoms (Aublet-Cuvelier et al., 2006; Bot et al., 2005).

One question regarding the disease course is whether it always starts with insidious symptoms, as described by Kuorinka and Forcier (1995), or whether there are different ways for the process to begin. In the disease course presented in paper III, the initial phase was becoming aware of the body; this was sometimes experienced suddenly, but in most cases it was more gradual. When becoming aware of the body, the informants retrospectively noticed their symptoms as a problem, as the recurrence and increased intensity of the symptoms made
them too intrusive to remain unrecognised. Lillrank (2003) found that the beginnings of the course of low back pain could be either a sudden and dramatic onset, or a gradual change from seemingly normal events to persistent back pain. This description fits with the findings of study III. However, study III also revealed the combination of a diffuse beginning with a noticeable first occurrence of symptoms. This indicates the possibility that some people may accept a lower level of symptoms as “normal”, until the occurrence of an isolated case of sudden pain. Different responses to differences in pain perception have also been described among people with neck and/or back pain (Hansson et al., 2006). New, intense, threatening pain made people call in sick more quickly, while in other sorts of pain, the timing and duration of the sick listing was a negotiation between self-image, work-duty norms, and organisational and extra-organisational work factors. In the present study, the informants continued working until their pain was experienced as being threatening and disabling; this probably resulted in their obtaining treatment at an unnecessarily late stage.

After becoming aware that the MSDs had developed, the informants described neck-shoulder symptoms which gradually progressed to being something always felt, a constant bodily illness. The results of recent studies (Bot et al., 2005; Pernold et al., 2005) indicate a disease course of new neck-shoulder problems with persistent symptoms and low recovery rates. The major improvement was seen within the first three months, and only minor improvements occurred thereafter. Disease courses are often described as linear processes with predictable steps, as trajectories (Corbin & Strauss, 1991; Granger et al., 2006) or transitions (Kralik, 2002; Shaul, 1997). The disease course of neck-shoulder disorders is not consistent with such disease courses, if the fluctuating course is not taken into consideration. The great variability in symptoms was described as a major problem in study III, as the unpredictability affected daily life and made it difficult to make and realise plans. The stress of the unpredictability of musculoskeletal disorders, and its severe implications for daily life, are well documented (e.g. Johansson et al., 1999; Miles et al., 2005).

Bodily illness related to MSDs is mostly characterised as pain, ache, and/or discomfort (Kuorinka et al., 1987), which are conventional descriptors of musculoskeletal disorders. During the disease course, moments of consuming intensity were also described in study III. Those included severe and more general symptoms of bodily illness, such as dizziness, nausea/vomiting, fatigue, difficulties in concentrating, and oversensitivity to sound and light. These are more extensive symptoms than are usually associated with MSDs. However, in a
review of epidemiological studies on musculoskeletal disorders, Malchaire, Cock, and Vergracht (2001) found similar associations between neck-shoulder disorders and symptoms of dizziness, gastrointestinal problems, fatigue, memory problems, irritability, sleeping problems, headaches, and depression.

**Low correspondence between experiences and questionnaires**

Even though there is increasing agreement over the value of taking the experiences of the affected into consideration in the development of health status measurements (Bombardier & Tugwell, 1987; Guyatt et al., 1993; Streiner & Norman, 1995; Hoving et al., 2003), this is still a rare practice in the area of musculoskeletal disorders. Of the nine questionnaires included in study IV, only two had made use of the opinions of people with neck-shoulder disorders in their development, and only one of these, PFM, had made the selection of items based on interviews. A number of researchers have highlighted the need to develop and choose instruments that fits the target group and the purpose of the evaluations (Hoving et al., 2003; Pietrobon et al., 2002).

The narratives of men and women with neck-shoulder disorders revealed a variety of symptoms related to such disorders. These symptoms showed bodily, mental/cognitive, and emotional engagement, and included more general and more severe symptoms than are usually found in MSD questionnaires. When all items in all questionnaires were taken together, many of the symptoms described in the interviews were included. However, most individual questionnaires only included a few of these symptoms. The questionnaire that was most in agreement with the interviews was the PFM, which included 15 different symptoms, while the other questionnaires included between two and six symptoms each.

Generally, some symptoms expressed in the interviews were missing, or less often considered, in the questionnaires. One such aspect relates to symptoms from the shoulder blade region which was included in the descriptions in the interviews, but not in the questionnaires. When looking at the body maps often included in MSD questionnaires, where symptom regions are depicted, it seems as if the shoulder blade is included in the shoulder region, and no differentiation between symptoms in shoulder and shoulder blade is considered. The question thus arises of whether a specification of the symptoms in the shoulder region could be useful. Mental and emotional experiences were also mostly excluded from the questionnaires. Since the results included in this thesis, as well as the results from other studies (Malchaire et al.,
2001; Hoving et al., 2003), indicate the importance of these dimensions, they should be considered in the development of new questionnaires. Emotional functioning has also been suggested by Dworkin et al. (2005) as one of six core outcome domains to consider when designing clinical pain trials, in order to improve the possibility of identifying treatment efficacy and to allow better evaluations.

Many neck-shoulder questionnaires are modifications of low back scales. A better approach might be to consider the content and items of several existing neck-shoulder questionnaires, and the experiences of people with the disorder, to increase the possibility of reflecting significant aspects of the disorder and thereby improve the content validity of the questionnaire.

In the interviews, the informants were able to distinguish a variety of different qualities of both functional symptoms and pain. Such nuances in symptom experiences were not usually considered in the questionnaires. Dworkin et al. (2005) have emphasised the value of investigating different quality and temporal aspects of pain, as various measures of these components are able to more fully describe a patient’s pain experience than would be possible using pain intensity alone. Such an approach to describing and measuring pain has been considered in general pain questionnaires, such as the McGill Pain Questionnaire (MPQ) (Melzack, 1975, 2005), which identifies a variety of pain descriptors categorised as sensory, affective, evaluative and miscellaneous. The McGill questionnaire also considers different temporal aspects, such as if the pain was experienced as rhythmic, periodic, intermittent, continuous, steady, or constant. The neck-shoulder questionnaires in our study generally did not take the variability of symptoms into account. As the disease course is recognised to have a great variability, including recurring symptoms (I-II) (Aublet-Cuvelier et al., 2006; Bot et al., 2005), both the qualities and the fluctuations of symptoms need to be considered. Taking such an approach to musculoskeletal disorders, that is, considering different quality and temporal aspects of pain, could increase the possibility of capturing the variability of symptoms. This would in turn create the possibility of increasing both the criterion-related validity (the ability to predict some criterion variable, such as the course of the underlying disease) and the responsiveness (the ability to detect small but important clinical changes) (Pietrobon et al., 2002).
To develop a condition-specific questionnaire, it is important to decide on the specific symptoms for the condition. A good way to do this is by using the experiences of those affected, combined with relevant research and professional knowledge. A combination of insider/outsider perspectives and qualitative/quantitative methods is necessary if we are to alleviate the suffering of the affected.

**Practical implications**

Out of the findings in present thesis some practical implications concerning prevention, treatment and rehabilitation can be drawn:

- Aspects of getting worn out and getting too vulnerable should be taken into consideration in prevention of MSDs in health care and ambulance service in addition to ergonomic aspects of work and physical training.

- In general, working with wellness parallel to illness can increase the possibility to prevent MSDs and relieve suffering.

- Mild, insidious symptoms should be seen as warning signals of something that can develop to a serious condition and should not be neglected in prevention. Risk groups should be aware of the importance of not neglecting such symptoms, and they should also be encouraged to take measures at an early stage to prevent development of neck-shoulder disorders.

- Increased knowledge, and a description, of the disease course of neck-shoulder disorders can be useful in prevention, treatment and treatment as communication about the disorder could be more specific.

- To increase the content validity of condition specific questionnaires for neck-shoulder disorders it is important to take the experiences of those affected into consideration. Symptoms to consider are general symptoms as dizziness, vomiting and feebleness, feeling out of sorts. Mental/cognitive symptoms were also described, as fatigue, difficulties to concentrate, and sensitivity to sound and light. Other symptoms to consider are emotional symptoms as irritation, irritability and sadness, depression. The fluctuation of symptoms during the disease course should also be considered in the development of
questionnaires, as there are calmer periods, intermittent impairment and intense peaks. A qualitative differentiation in nuances of symptom descriptions should also be considered in questionnaires.

**Methodological considerations**

The methods used in this thesis are discussed separately, against the concepts that usually are presented in relation to each method in literature on qualitative methods. The trustworthiness of the findings in the studies using grounded theory is discussed in relation to the concepts of emergence, theoretical sensitivity, theoretical sampling, saturation, fit, work, relevance and modifiability, and rigor (e.g. Chiovitti and Piran, 2003; Glaser & Strauss, 1967; Glaser, 1992; Hartman, 2001). In the studies using content analysis trustworthiness is discussed in relation to credibility, dependability and transferability (Lincoln & Guba, 1985; Polit & Hungler, 1995).

**Design**

The qualitative approach of this thesis, using grounded theory and content analysis, gave an opportunity to gain insight into how MSD can be experienced. This approach made it possible to explore the health experiences of occupationally active men and women with MSD (I-II). It also made it possible to further explore the disease course of chronic neck-shoulder disorders (III) and the symptoms experienced during it (IV). Out of these studies it was possible to compare symptoms experiences to questionnaires (IV).

Male ambulance personnel and female health care personnel were chosen in study I and II in order to get insight into the health experiences of occupationally active men and women with MSD. Both groups were chosen as they are occupational groups that are known to have high numbers of people affected by MSD and as they are male and female dominated respectively. As there is a lack of studies of experiences of MSD in early stages, it was important to include participants still active in working life who probably not are severely affected by the disorder. There are also differences between men and women in both the prevalence of MSDs, and the risk of getting the disorder (eg. Wijnhoven et al., 2006), so studies concerning experiences of MSD should separate men and women in the analyses. To reach saturation in our findings we made some choices during the theoretical sampling based on previous findings. Among the ambulance men further informants were chosen to get variation in age and years in the occupation, as data indicated different experiences that we wanted to further explore. Among
the women in health care we initially included women at different wards in one hospital, thereafter we included women at different wards in two other hospitals as questions regarding different experiences related to differences in context and culture arose.

Efforts to ensure theoretical sensitivity were made by trying to enter the field with as few predetermined ideas as possible, by having an initial openness in recruiting informants and interviewing them, followed by a theoretical sampling in different contexts, and by using questions that arose during the analysis (Coyne, 1997; Glaser, 1978). As the findings in study I and II woke the interest to further explore the bodily illness experiences, a new analysis was made in study III of the previously performed interviews, added by seven other available interviews. Thereafter a theoretical sampling was made for study III in order to get informants from other contexts than health care and with only neck-shoulder problems. This latter sampling procedure was performed as the analysis indicated differences in experiences related to neck-shoulder and low back disorders. Hence, study III included people affected by neck-shoulders symptoms in different stage. The interviews with people with neck-shoulder problems were also used in the analysis in study IV, as it was possible to further investigate the symptom experiences of the affected. The neck-shoulder questionnaires in study IV were chosen based on a systematic review of scales 1966-2000 performed by Pietrobon and colleagues (2002). A complementary search via PubMed was performed to update the sample to 2001-2007.

Data collection
Data collection was performed using narrative (I-II-III) and semi-structured (III-IV) interviews, as well as a review of neck-shoulder questionnaires and the articles presenting them (IV). The narrative interviews started openly, to leave the field as open as possible for the informants. “Tell me about how you perceive your health” was the opening question, and during the interviews efforts were made to be attentive and follow up interesting leads. The parallel transcription and analysis of interviews made interesting leads visible, which were followed up during forthcoming interviews. A map of different themes to explore was developed and revised during the period of doing the narrative interviews. During the project the interviews and how they evolved was discussed in the research group. In the semi-structured interviews for study III and IV a question guide was used, which was developed based on the initial analysis in study III of the narrative interviews in study I and II. The questions, and the follow-up questions, were aimed to further explore the disease course (III),
and get as full descriptions of their symptoms as possible (IV). All interviews included in present studies were performed by the same interviewer, (BW), except the seven with operating room nurses (study III). Those interviews were performed by a female master student, who used a similar theme map as I did. The participants had the opportunity to choose where the interviews should take place, except for the informants with neck-shoulder problems in study III-IV which were interviewed in an office at the University of Gävle. This was convenient for the informants as they had visited the test laboratory at the university just before the interviews took place. Efforts were made to make the interview situation as comfortable as possible for the interviewee by making the room feel friendly, and by starting with contextual issues and asking them to tell about them selves.

Data analyses

During the research process questions with regard to the fit, work and relevance of the emerging categories and relationships between them were discussed, as suggested by Glaser (1978), to continually fit the analysis to the data. In the conceptualisation the descriptions of the informants were used wherever possible, to enhance rigor as suggested by Chiovitti and Piran (2003). The attempt in this research was to enter the field with as few predetermined ideas as possible. To have no previous professional role in the field of MSDs was experienced as beneficial when using Grounded Theory. However, my experiences as a woman and a nurse could have affected the interpretation, for example, of the findings in study II since it was much harder for me to see the gendered issues for the women. However, to increase credibility the authors in respective study have considered reflexivity by using their different experiences gained through work as nurses, physiotherapist, lecturer and researchers in discussing the interviews, performing the analysis and formulating the resulting codes, categories and model. The opportunity to discuss the analysis and the findings with other researchers in different groups and on seminars were also used, and the informants were asked to reflect on different aspects during the process.

In data collection and analysis of study II an open approach and emerging design was applied, assuming that the experiences of female health care personnel would be quite different from those of male ambulance personnel. But, as the data in study II indicated the same core category as well as the same basic social psychological process as in study I, the model was modified to rely on the emerging categories. The literature on grounded theory presents different criteria used to evaluate a theory. While Strauss and Corbin (1998) write about the
possibility to reproduce and generalise, Glaser has retained the criteria of relevance, function and modifiability (Glaser & Strauss, 1967). Modifiability means that a theory grounded on data has to be modified according to new discovered data, and sometimes a changing reality, to stay relevant and thereby work (Hartman, 2001). In study II did the content of some categories differ compared to study I, and the process of balancing was also clarified. During the process of analysis and rewriting, it became clear that “striking a balance” (study I) points at a static condition, while “striving for balance” (study II) would be a more suitable description for the process in both studies as it describes a continuously ongoing process. Therefore “striving for balance” is used as core category when describing the results in this frame story.

An important question is if the described process of balancing is unique for the health care context, or if it is transferable to others? This issue relates to the level of the developed theory, as being substantive/empirical or formal. Hartman (2001) describe a substantive theory as one that concern a specific area, for example a certain group of people. A formal theory is on a higher level. It is not about the meaning a phenomenon has for example for a certain group of people, but about the phenomenon it self. According to Glaser and Strauss (1967), is it up to the reader to judge the transferability of a substantive theory to another context and thereby compare the relevance and workability. By comparing the findings of the studies (I-II) of this thesis with other studies where balancing has been used to describe experiences in relation to illness, the process seems to be common, and other studies also includes elements comparable to present model (Beanlands et al., 2007; Kristofferzon et al., 2007; Paterson et al., 1998)

In content analysis are credibility, dependability and transferability discussed in relation to trustworthiness (Lincoln & Guba, 1985; Polit & Hungler, 1995). Credibility in content analysis often refers to how well the constructed themes reflect the informants’ experiences in interviews, while transferability refers to the degree to which the results are transferable to other contexts and groups. In study IV the categorisation of the interview data was made relying on interviews with 40 informants, to get a large amount of data. In the categorisation the codes/symptoms are presented, and the words of the informants are used as much as possible, to make it possible for the reader to judge the credibility, as well as the transferability. Frequencies of occurrence of symptoms were also added so the reader can conclude how common presented symptoms were in the group. When making the categorisation of the symptoms descriptions from the interviews, two professional in the area
of MSD was asked to categorise an alphabetically ordered list of codes/symptoms into categories that made sense seen from their perspective. This corresponded well with our categorisation. In the categorisation of the questionnaires the items included in the different questionnaires are presented. Dependability in content analysis refers to the stability of data over time and over contexts. To clarify this, efforts were made by presenting data on informants and questionnaires, and also by presenting the whole categorisation of both interviews and questionnaires.

### Summary in Swedish – svensk sammanfattning

Det övergripande syftet med denna avhandling var att utforska och beskriva hälsoupplevelser bland män och kvinnor med muskuloskeletala besvär.

De fyra olika delstudiernas specifika syften var:

(I) att utforska upplevelsen av illabefinnande och välbefinnande bland ambulanspersonal med muskuloskeletala besvär

(II) att utforska upplevelsen av illabefinnande och välbefinnande bland kvinnlig hälso- och sjukvårdspersonal

(III) att utforska upplevelsen av kroppsligt illabefinnande bland människor med muskuloskeletala besvär i nack-skulder regionen

(IV) att utforska de symtom människor med muskuloskeletala besvär i nack-skulder regionen beskriver

att utforska vilken metod som använts för att utveckla frågeformulär vilka avser att mäta smärta och andra symtom bland personer med nack-skulderbesvär;

att analysera innehåll och items i dessa frågeformulär;

att jämföra fynden från intervjuer och frågeformulär.

Övergripande visar fynden att yrkesaktiva män och kvinnor med muskuloskeletala besvär ”strävade för balans” (I-II); att sjukdomsförfallet vid kroniska nack-skulderbesvär karaktäriserades av ”okontrollerbara fluktuationer” (III); och att de flesta Nack-skulder formulär hade låg överensstämmelse med den mångfald av symtom som upplevdes under sjukdomsförfallet (IV).
I processen att sträva efter balans (I-II) upplevde informanterna både illabefinnande eller välbefinnande i varierande grad vid olika tillfällen. Balanserandet startade när illabefinnandet blev för påträngande och var en process för att minska illabefinnandet. Genom att acceptera och hantera illabefinnandet och samtidigt uppnå och behålla välbefinnande kunde informanterna ”må bra nog”. Informanterna fortsatte att arbeta för att därmed få näring vilket var viktigt för att upprätthålla balansen. Även andra åtgärder vidtogs för att upprätthålla balansen och minska på illabefinnandet. För både männen och kvinnorna var illabefinnandet karaktäriserat av en upplevelse av kroppen som sviker, av sårbarhet och av utmattning. Illabefinnandet balanserades av välbefinnande, där vissa skillnader kunde ses mellan männen och kvinnorna. Medan männen kunde finna näring till sitt välbefinnande genom bland annat upplevelser av att vara ”någon”, göra skillnad och genom upplevelser av spänning och utmaning, kunde kvinnorna finna näring till sitt välbefinnande bland annat genom att uppleva sig vara till nytta, och genom att njuta av de små sakerna i tillvaron.

Sjukdomsförloppet i delstudie III beskrevs som okontrollerbara fluktuationer som vanligen utvecklades från smygande symtom till ett tillstånd av konstanta besvär. Deltagarna upplevde lugnare perioder under förloppet, men också ständigt återkommande skov av försämringar och tillfällen med besvär av mycket stark intensitet.

Intervjuerna i delstudie IV inkluderade en mångfald av symtom, vilka indikerade ett kroppsligt, mentalt och emotionellt engagemang, med mer generella och kraftiga symtom än de som vanligen kopplas till nack-skulderbesvär. Få frågeformulär var utvecklande på bas av erfarenheter av drabbade personer. Tagna som en helhet, täckte frågeformulären många av de drabbades symtom, men varje formulär i sig inkluderade bara ett fåtal symtom. Fluktuationer i symtom och olika nyanser var sällan beaktade. Överensstämmelsen mellan de enskilda frågeformulären och de drabbades upplevelser var oftast låg.

Denna avhandling visar att andra hälsoaspekter än enbart kroppsliga upplevs som viktiga bland yrkesaktiva människor med muskuloskeletala besvär. Den tillhandahåller också en beskrivning av sjukdomsförloppet vid nack-skulderbesvär, samt en indikation på möjligheter till förbättring av nack-skulderformulär.
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