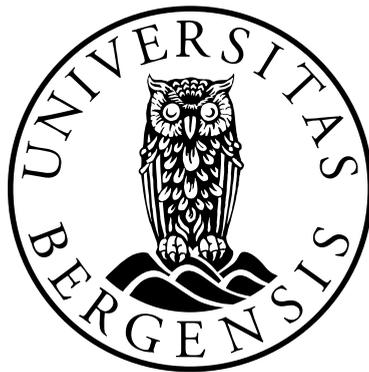


**Sick leave for patients with
severe subjective health complaints**
Challenges in general practice

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Scientific environment

The work presented in this thesis has been conducted at Uni Health, Uni Research. The thesis was carried out within the institutional framework of the doctorate program at the Faculty of Psychology, University of Bergen, Department of Health Promotion and Development (HEMIL), Graduate School of Human Interaction and Growth (GHIG).

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My supervisors were Professor Hege R. Eriksen, PhD, Professor Kirsti Malterud, MD, PhD, Senior Researcher Erik L. Werner, MD, PhD, and Professor Maurice Mittelmark PhD.

Preface

As a physiotherapy student I viewed private physiotherapy practice as the ultimate place to work. The thought of having patients coming to me for help seemed glamorous, fun, and challenging. However, as a clinical physiotherapist, I never actually came to work in private practice, where patients with severe subjective health complaints (SHC) are frequently seen. My clinical work revolved around specialist hospital care and rehabilitation, mainly treating patients with neurological conditions. I am a team player, and my best professional experiences have been in multidisciplinary teams solving health related challenges together with the patients.

To me, it has been difficult to understand what severe SHC really is, and why some individuals suffer more than others. This is a continuous journey, constituting an important part of the context for this thesis. The theoretical backdrop of my research group based in psychology and behavioural medicine, supplemented with general practice, has resulted in a professional shift for me from a purely biomedical view, in which I was trained as a physiotherapist in the United Kingdom in the mid 1990's, to a biopsychosocial understanding of illness and disease. Getting insight into the health complaints of patients with severe SHC through the perspective of general practice and the general practitioner (GP) has given me a unique opportunity to understand more about a complex clinical field.

I would like to thank:

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Special thanks go to my very patient and fantastic husband Ketil. Thanks for waiting and for organizing the building of our future favourite place on earth in solitude.

Thanks also to our beautiful and understanding children Sunniva, Gustav and Wilhelm; for always being there for me and reminding me that the most important thing in life is not a PhD. Now we can commence our normal lifestyle and preferred way of living Nunna♥

Bergen, May 2012

Silje Mæland

To “Besse” who never got the opportunities I did♥

Abstract

The main purpose of this thesis was to contribute to a better understanding of factors that are important when general practitioners (GPs) make decisions for sick leave for patients with severe subjective health complaints (SHC). The thesis includes three papers that all deal with different aspects of this topic.

The first paper describes which diagnoses GPs in Scandinavia apply for patients with severe SHC. In the second paper, factors important for sick leave decisions in this group of patient are explored. The third paper deals with GPs' arguments for not wanting to participate in a study where patients would be randomized to sick leave. Paper I and II are based on a questionnaire from a cross sectional study in Norway, Sweden and Denmark where GPs watched dramatized video vignettes of a GP encounter of patients with severe SHC. Paper III is a qualitative study with web-based written responses from Norwegian GPs to an open-ended question about why they were unwilling to participate in the trial.

GPs in Scandinavia applied a large variety of diagnoses to the same patients, but the diagnosis was not the fundamental factor determining sick leave decisions. Sick leave decisions were based on assessment of the patient's work-ability and risk of deterioration if they continued working. Diagnostics and sick leave decisions in patients with severe SHC are complex and individualized tasks, also based on the GP's knowledge about a patient's personality, vulnerability, and family situation. These assessments require professional clinical skills of a GP, but deciding on sick leave in the end seems to be a joint decision between the GP and the patient. The findings in this thesis shed light on the GPs' dilemmas of the potentially conflicting roles of being a gatekeeper for the society versus being an advocate for the patients. Since the primary diagnosis on the sick leave certificate forms the basis for national sick leave statistics the variance in these diagnoses affects the reliability of these statistics.

Sammendrag

Hensikten med denne avhandling var å bidra til en større forståelse av hvilke faktorer som er viktige når allmennleger vurderer sykmelding for pasienter med alvorlige subjektive helseplager. Avhandlingen er basert på tre studier som alle belyser dette emnet.

Den første artikkelen beskriver hvilke diagnoser allmennleger i Skandinavia gir pasienter med alvorlige subjektive helseplager. I den andre artikkelen ser vi på hvilke faktorer som har betydning for sykmeldingsavgjørelser for disse pasientene. Den tredje artikkelen handler om hvorfor allmennleger ikke vil delta i en studie der pasienter randomiseres til sykmelding. Artikkel I og II er basert på norske, svenske og danske allmennlegers svar på et spørreskjema i en tverrsnittstudie. Dette ble besvart etter å ha sett ni videovignetter av pasienter med alvorlige subjektive helseplager i deres møte med allmennlegen. Artikkel III var en kvalitativ studie hvor allmennleger i Norge forklarte hvorfor de ikke var villig til å delta i en studie med randomisering av sykmelding. Svarene var web-baserte svar på et åpent spørsmål.

Allmennleger i Skandinavia ga mange forskjellige diagnoser til samme pasient, men diagnosen var ikke det avgjørende for sykmeldingsbeslutninger.

Sykmeldingsbeslutninger var basert på en samlet vurdering av pasientens arbeidsevne og fare for forverring dersom han eller hun fortsatte å jobbe. Diagnoser og sykmeldingsbeslutninger for pasienter med alvorlige subjektive helseplager er komplekse og basert på vurderinger av hvert enkelt individ der legens kunnskap om pasientens personlighet, sårbarhet og familiesituasjon også spilte inn. Vurdering av behov for sykmelding for disse pasientene bygger på allmennlegens profesjonelle og kliniske kunnskap. Til syvende og sist baseres avgjørelsen på en felles forståelse mellom legen og pasienten. Funnene i denne avhandlingen belyser allmennlegers dilemma knyttet til de potensielt motstridende rollene som henholdsvis samfunnets portvakt og pasientens advokat. Ettersom primærdiagnosen en lege setter på en pasient danner grunnlaget for sykefraværstatistikker er det grunn til å stille spørsmål ved gyldigheten og nytten av statistikk basert på sykmeldingsdiagnosene.

Abbreviations and definitions

CATS - the Cognitive Activation Theory of Stress

CME - Continued Medical Education

CSS - Cross Sectional Survey

DSM IV - Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)

GP – General practitioner (UK), family physician (US)

ICD-10 – International Classification of Diseases

ICD-10 PHC - Primary Care Version of International Classification of Diseases (10th Revision) Chapter V. for Mental and Behavioral Disorders

ICPC-2 – International Classification of Primary Care, second edition paper

ICPC-2-E - International Classification of Primary Care, second edition electronic version

lme4 library – Linear mixed-effects models using S4 classes

MUS – medically unexplained symptoms

N - Number

OECD – Organisation for Economic Co-operation and Development

PAWS – Predictive Analytics Soft Ware

RCT – Randomized controlled trial

REC West - The Regional Committee for Medical and Health Research Ethics, Western Norway

SD – Standard deviation

SHC - Subjective Health Complaints

SHC Inventory - Subjective Health Complaints Inventory

WHO – World Health Organisation

WONCA - World Organization of National Colleges, Academies and Academic Association of General Practitioners/Family Physicians

WICC – WONCA International Classification Committee

List of publications

- I. Maeland S, Werner E.L, Rosendal M, Jonsdottir I.H. Magnussen L.H, Ursin H, Eriksen H.R.
Diagnoses of patients with severe subjective health complaints in Scandinavia. A cross sectional study
(Submitted)

- II. Maeland S, Werner E.L, Rosendal M, Jonsdottir I.H, Magnussen L.H, Lie S.A, Ursin H, Eriksen H.R.
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- III. Maeland S, Magnussen L.H, Eriksen H.R, Malterud K.
Why are general practitioners reluctant to enrol patients into a RCT on sick leave? A qualitative study

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1. Introduction

Patients with severe Subjective Health Complaints

Musculoskeletal pains, tiredness, sleep disturbances, and feelings of depression or anxiety are common health problems in the general population (1). Over the last month, the large majority (95 %) of a representative sample of the Norwegian population (1) and over the past 2 weeks, 72% of a representative sample of the Danish population (1-2), had experienced at least one such complaint or symptom. These complaints or symptoms account for a substantial proportion of the encounters in general practice (3). Some complaints may be symptoms of disease, but for most individuals, these complaints are normal complaints (1), self-limiting and with a good prognosis (4).

For some people however, such complaints become *chronic* and develop into long-standing conditions or syndromes. Chronic low back pain for example is a quite specific description of a condition where an individual has been experiencing long lasting pain in the lumbar region of the spine. In other cases, the condition may involve chronic widespread pain such as fibromyalgia. Sometimes clusters of health complaints are defined as syndromes, such as chronic fatigue syndrome or irritable bowel syndrome. Several *terms* are used for persistent symptoms and complaints without obvious pathology and unclear aetiology (see Table I next page) (5). The usefulness of the different terms, for the patient, the GP, and society has been debated, but so far, no term has been found satisfactory or useful for all stakeholders (5).

In this thesis the term *subjective health complaints* (SHC) is used because this term acknowledges the complaints as subjective experiences of bodily sensations with varying degrees of discomfort, severity and disability (6-7). Furthermore, the explorations of this thesis are in the more disabling end of the SHC continuum identified by adding '*severe*', thereby approaching a group of patients suffering from

long lasting conditions which limit their function in activities such as work outside the home, domestic work or leisure activities and represent a considerable burden of suffering. The large number of different terms for these complaints or conditions represents a challenge in getting an overview of who these patients are. It also indicates that this is a complex medical field where specialists do not fully agree on how medicine shall understand these conditions. The terms represent some differences, but in general they all try to provide useful names to conditions and disorders that have something in common.

Table I: Different terms for persistent symptoms and complaints without obvious pathology and unclear aetiology.

| |
|--|
| Bodily distress syndrome/disorder |
| Bodily stress syndrome/ disorder |
| Medically unexplained symptoms (MUS) |
| Functional disorder |
| Functional somatic syndromes |
| Medically unexplained disorders (MUD) |
| Medically unexplained physical symptoms (MUPS) |
| Psychological/psychophysiological disorder |
| Psychosomatic disorder |
| Somatic symptom disorder |
| Somatoform disorder |
| Subjective health complaints (SHC)* |
| Symptom defined illness or syndrome |

Modified from Creed et al (5).

*This term is not included in Creed et al (5)

The general practitioner (GP) is the medical professional who usually is in charge of diagnosis and follow-up of patients with such conditions (4). The prevalence of these conditions in primary care varies substantially between studies depending on which diagnostic tools and terms are applied (8-14). Steinbrecher et al (14) for example, use the term MUS in their prevalence study and find that two-thirds of consecutive patients in primary care in Germany have at least one medically unexplained (64.8%)

or a mix of explained and unexplained (76.7%) complaints. In this study the authors also include somatoform disorders in MUS (14). Another example is from Denmark where 15% of the general population report that they are limited in their daily activities due to MUS (2). The large variation in prevalence may therefore be explained by researchers using different definitions, ways of surveying prevalence and different diagnostic tools, thereby including different subgroups of patients.

Rosendal et al (15) have suggested an arbitrary cut-off point of three symptoms for the diagnosis 'MUS'. To distinguish between mild and severe 'MUS' a six-month duration is suggested (15). However, the cut-offs for duration and number of complaints are debated (15). While some researchers suggest number of complaints to be an indicator of severity and burden of disease (16-17), others have highlighted that some patients experience disabling health with few complaints and that there are no obvious cut off (1).

A linear relationship between the number of musculoskeletal and non-musculoskeletal complaints indicates that there may be common characteristics and underlying causal factors in these conditions (17). *Sensitisation* has been suggested as a common underlying pathophysiological mechanism for why common symptoms and complaints may develop to severe SHC (18). Sensitisation is a psychoneurobiological phenomenon leading to decreased thresholds for set-points of normal physiological processes and sensations (such as pain and stress (18-19). Sensitisation in neural loops, sustained attention, level of arousal and outcome expectancies (positive, neutral and negative) that are based on previous experiences, can be understood through the *Cognitive Activation Theory of Stress* (CATS) (20). In some individuals, low levels of coping, together with high levels of perceived hopelessness and helplessness may result in severe SHC (18, 20).

There are other explanatory models for these conditions that focus on different domains. Some models aim at physical explanations, some at psychological explanations, and others choose a combination of the two (21) proposing why these complaints may develop into severe and disabling conditions. A list of possible

models is presented in Table II. I will not explore these in further detail in this thesis. CATS is chosen as a theoretical framework for understanding why some patients develop severe SHC because the CATS theory (20) is based on psychobiological data. The concept of sustained activation in non-coping individuals offers psychobiological sensitisation as an explanation both of the multimorbidity and the unexplained nature of severe SHC (18, 20). To me, this model gives a thorough understanding of how former experiences can influence perceptions and offer an explanation to why some individuals develop severe SHC.

Table II: Explanatory models for why SHC may develop into severe SHC in some individuals

| |
|---------------------------------------|
| Autonomous nervous system dysfunction |
| Abnormal proprioception |
| Endocrine dysregulation |
| Illness behaviour model |
| Immune system sensitization |
| Sensitization |
| Sensitivity |
| Signal filter model |
| Somatosensory amplification |

Adapted from van Ravenzwaaij et al (21).

Patients with SHC usually report several complaints (11, 22-25). Different terminology is used to describe this co-existence of complaints. Comorbidity, multimorbidity, burden of disease and frailty are often used interchangeably (26). According to Valderas et al (26) the term comorbidity implies that there are primary and secondary disorders or diseases based on chronology of the co-occurring conditions. The term *multimorbidity* seems to be more appropriate in patients with severe SHC, as it highlights that two or more complaints co-exist without any implicit ordering. Furthermore, in general practice identifying and acknowledging this co-existence of complaints is thought to be important to understand the patient and improve clinical care (26). In this thesis, taking the GP context as my point of departure, I therefore choose the term multimorbidity throughout.

Diagnosis of medical problems

Diagnosis is derived from the Greek words *dia* (between) and *gignoskein* (to know or distinguish), meaning, ‘to know between’. The purpose of a diagnosis is to interpret patients’ health complaints and diseases, to provide adequate treatment, and predict prognosis in everyday practice. Other purposes for diagnostic activity are research, access to social benefits, insurance reimbursements, or forensic purposes. Diagnoses are also used for communication regarding medical conditions between doctors, between doctors and patients, and between doctors and the social security system. A diagnosis may also be used simply because it offers legitimate rights to social benefits (27).

Medical diagnoses are traditionally categorized according to anatomical organ chapters. The *International Classification of Primary Care, Second Edition (ICPC-2)* is the predominant diagnostic taxonomy in European primary care (28). It was developed by the World Organisation of Family Doctors (WONCA) in 1987 and recognized as a classification for primary care by WHO in 2003 (29). The ICPC-2 system contains 17 chapters; 14 biomedical organ chapters, one chapter for psychological problems, one chapter for social problems, and one general chapter for disease and complaints that do not fit into any of the other chapters (see Appendix 2).

As opposed to the diagnostic taxonomies applied in specialist care, ICPC-2 allows coding for complaints or *symptoms diagnoses (A-Z 1-29)*, not only for established *disease diagnoses (A-Y 70-99)*. Symptom diagnoses are commonly used as working hypotheses when the patient is under investigation (30), or while awaiting a natural resolution which does not require medical intervention. The ICPC-2 has been translated into 32 languages (31) and is currently in use in primary care in many countries (29), including Norway. In Norwegian specialist care the International Classification of Diseases (ICD-10) is used (32). Until now, Danish GPs have not used any uniform classification tool for diagnosis registration; some have used ICPC-1, others the ICD-10 (32). Denmark is currently in the process of implementing the ICPC-2 as a mandatory classification tool for medical records in primary care. All

Danish GPs shall have this implemented by the end of 2013. Another classification systems used in primary care is the International Classification of Diseases in Primary Health Care (ICD-10 PHC) (33). This is used in Sweden and offers a simplified version of the ICD-10 (32).

Clinical examination, diagnostic tests and laboratory findings are important to doctors when deciding on what is wrong with a patient. However, the patient's history is actually the most significant basis for diagnosing (34). Information from the patient is important in this encounter, and what he or she decides to share with the doctor, influences the choice of diagnosis. For disorders, such as in patients with severe SHC, deciding on a diagnosis may be a challenging task, depending on the purposes of the diagnosis in the specific clinical context. In terms of providing relief or legitimizing the patients problems giving diagnostic labels, like fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome, may not be useful and helpful for the patients (35-36).

A diagnostic label has been shown to be important to the patient, who prefers a medical label like 'gastroenteritis' rather than a lay label like 'stomach upset'. A medical label validates the social role of being sick and improves the patients trust in the GP (37) or the patients role as a sick person (36). However, diagnoses do not give a complete picture of a patient's condition (38). Hence, there is still much to learn about diagnostic work in general practice (35, 39).

The medical records in general practice will not fully reflect or project the multimorbidity and sometimes unexplained, character (30) seen in patients with severe SHC. When a GP, in Norway, grants a patient sick leave, one single medical diagnosis, coded according to the ICPC-2, is written on the sickness certificate. This is done because according to Norwegian Law, an individual has to have a disease, illness, injury or disability to be entitled to sickness benefits. In the 'Norwegian Insurance Act' (40) the concept of disease is not defined, but it is written that it should be assessed based on what medical science at any time defines as a disease (40).

Severity of a condition is poorly captured by the diagnostic systems (41). The diagnostic label irritable bowel syndrome for example, does not tell whether the patient has mild, moderate, severe, or very severe complaints. Diagnoses for patients with severe SHC are often classified either in the chapter of psychological problems (P) or as syndrome diagnoses based on predefined symptom checklists and the exclusion of other organ pathology (15). See Table III for examples of which diagnoses patients with severe SHC may get in the different taxonomies.

Table III: Diagnostic criteria applicable to Medically Unexplained Symptoms (equivalent to severe SHC) in ICPC-2, ICD-10 and DSM-IV.

| ICPC-2 | ICD-10 | DSM-IV |
|---|---|--|
| Somatization disorder (P75) | Somatoform Disorders (F45) | Somatoform Disorder (300) |
| <p>Persisting and multiple physical symptoms and demands of examinations despite negative results and reassurance from the doctor.</p> <p>Symptom duration > 12 months</p> | <p>Physical symptoms and persistent requests for medical investigations, in spite of negative findings and reassurance. Symptom duration ≥ 6 months</p> <p>F45.0 Somatization disorder (symptom duration ≥ 2 years)</p> <p>F45.1 Undifferentiated somatoform disorder</p> <p>F45.2 Hypochondriacal disorder</p> <p>F45.3 Somatoform autonomic dysfunction</p> <p>F45.4 Persisting somatoform pain disorder</p> <p>F45.8 Other somatoform disorders</p> <p>F45.9 Somatoform disorder, unspecified</p> <p>F44 Dissociative disorder</p> | <p>Physical symptoms that no diagnosable general medical condition fully can account for. The symptoms cause clinically significant distress or impairment.</p> <p>300.81 Somatization disorder (at least eight unexplained symptoms, duration ≥ 2 years)</p> <p>300.81 Undifferentiated somatoform disorder</p> <p>300.7 Hypochondriasis</p> <p>307.8 Pain disorder</p> <p>300.7 Body dysmorphic disorder</p> <p>300.81 Somatoform disorder NOS</p> <p>300.11 Conversion disorder</p> |
| Related diagnoses | Related diagnoses | Related diagnoses |
| <p>P02 Acute stress reaction</p> <p>P29 Psychological symptom/complaint, other</p> <p>P78 Neurasthenia</p> <p>P99: Psychological disorders, other</p> <p>Specific syndrome diagnoses as for example:</p> <p>D93 Irritable bowel syndrome</p> <p>Symptom diagnoses (1-29) from all organ chapters A to Y</p> | <p>F22.8 Persisting delusional disorders</p> <p>F48.0 Neurasthenia</p> <p>F68.1 Factitious disorder</p> <p>Syndrome diagnoses as for example</p> <p>K58 Irritable bowel syndrome</p> | <p>300.1 Factitious disorder</p> |

Patients with severe SHC encountering the GP

Norwegian general practice is a list-based system in which every inhabitant has the right to be on a GPs list of patients. Each GP can have up to 2500 patients on their list, but may limit their list below this level. The average number of patients in 2011 was 1200 (42). The salary for the GP is a mix of a capitation fee and fee-for-service. The relationship between the GP and the patient is formalized, and the GPs are responsible for planning and coordinating individualized preventive work, diagnosis, treatment and follow-up of the patients on his or her list. GPs are also responsible for the patient's medical records, medication and sick listing. Primary health care is the foundation of the Norwegian health care system, with the GP as a mandatory gatekeeper, providing referrals to specialist service when necessary. The GPs are therefore typical representatives for what Lipsky (43) has described as 'street-level bureaucrats'. A central point in Lipsky's theory is that the 'street-level bureaucrats', the GPs, are frontiers in the bureaucracy that face-to-face have to execute political decisions (43). This may result in considerable dilemmas when caring for patients.

The main care of patients with severe SHC falls upon their GP (3). One of the core features of general practice is the long-term and continuous relationship between doctors and patients (44). The doctor-patient relationship is especially important for these patients (45-46). In the past years, an increasing interest from clinicians and researchers, has been shown to this broad and heterogeneous group of patients (47). In a study among British GPs, more than 80% of the GPs felt that they provided the most effective management for these patients (3). Still, some GPs feel unable to explain disease mechanisms to the patient (48). Several studies have reported that some GPs feel more challenged by patients with severe SHC than by patients with more specific conditions, particularly regarding the issues of treatment and sick listing (49-50). When medical assessment, tests and investigations does not indicate disease, some GPs may try to reassure the patients by telling the patient that there is no disease and try to normalize the symptoms (48). However, such a strategy may actually result in more health-care seeking (51).

The doctor-patient relationship is unequal regarding power - the GP is the expert and may acknowledge or dismiss the validity of the patients' complaints (27). When the GP feels certain that the patients complaints should be categorized as severe SHC, he or she will often approach the psychosocial circumstances and give advice on activities and coping. If this strategy fails, the GP may choose to focus on the relationship through mutual alliance and ritual care (such as regular physical examination, referral to physiotherapists, prescribing medical investigations) (48). This may lead to inadequate recognition and management of these patients (41). It has been argued that numerous investigations and referrals may be the GPs' way of coping with hopelessness (52) and stress (53) in these encounters. However, a qualitative analysis of 36 audio-recorded consultations between patients and GPs revealed, that most patients did not request symptomatic interventions (52) but seek emotional support from their GP (54).

The multimorbidity and complexity of patients with severe SHC may explain why some GPs perceive these patients as "difficult" (3, 50, 53, 55), and refer to them as 'heart sink' patients (56). Doctors are expected to provide medical treatment for the various conditions, but with severe SHC, the lack of medical explanations and the lack of obvious solutions frustrates patients as well as doctors (48, 52, 55). When it is difficult to meet the patient's expectations, the climate for a mutual understanding becomes difficult. The lack of biomedical explanations and resulting difficult clinical management has been highlighted to add to the complexity (52, 55). The GPs in the study by Steinmetz and Tabenkin (55) expressed frustration over patients with repetitive complaints that they rarely resolve, and if they managed to resolve a problem another one immediately appeared. This frustration seemed to decrease with the GPs experience and age.

Sick leave

The Norwegian social security system provides daily cash benefits with 100% of pensionable income, up to 6G. G is a basic amount of money (2011/2012: NOK 79 216) which is used in the calculation of Norwegian social security benefits.

Employers pay cash benefits for the first 16 days of sick leave, while the national social insurance system covers the wage loss from the 17th day up to a maximum of 52 weeks. After that period, the patient is covered by a work assessment allowance for up to two years and eventually, permanent disability pension. Self-certification in case of sickness may be used within the first three to eight days with a total of 24 days during a 12 month period if the person works in an inclusive workplace (IW) enterprise. The IW enterprises have signed the Cooperation Agreement for a More Inclusive Workplace aiming to increase participation in working life by systematic cooperation to satisfy the goals of a more inclusive workplace (57).

About half of all long-term sick leave certificates in Norway are issued for musculoskeletal and psychological complaints (58). Musculoskeletal, Psychological, and General and Unspecified diagnoses stand for 63% of all long-term sick leaves. Previous findings have documented that the majority of lost sick leave days are due to diagnoses based on subjective statements from the patient (59). Patients with SHC and severe SHC are therefore important target groups if the aim is to reduce sick leave. Norwegian GPs certify 79% of all long-term sick leave (60), and in some cases, GPs find management and sick leave decisions challenging and difficult (53) (50, 61). Lack of training to manage difficult sick leave decisions has been highlighted (62-63). Rosendal et al (64) showed that GPs' attitudes towards patients with somatoform disorders changed significantly after a brief multifaceted training programme, and the participants felt more comfortable dealing with these patients after the intervention (64). Figure 1, shows long-term sick leave statistics, in 4th quarter of 2011, categorized according to ICPC-2 chapters.

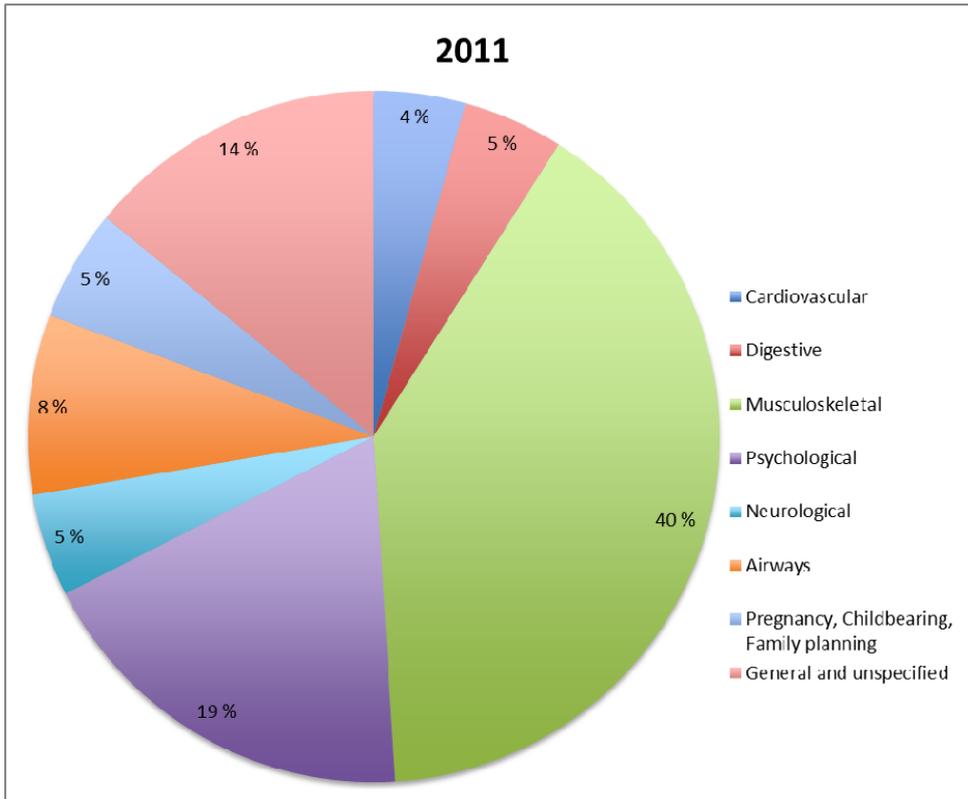


Figure 1: Norwegian long term sick leave statistics, 4th quarter 2011 presented according to ICPC-2 chapter.

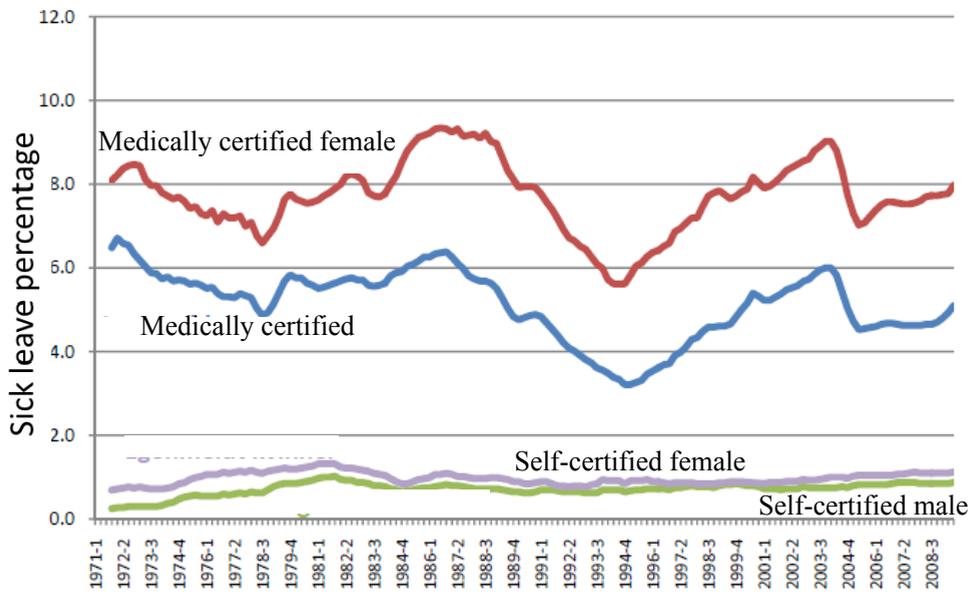
Decisions on sick leave are influenced by GP characteristics, however the results vary between studies. Some studies report that female GPs sick list more often than male GPs (65), others that male GPs sick list more than female GPs (63, 66), or that there are no gender differences in attitudes or sick leave prescription rate and length between GPs (67-68). Older GPs tend to sick list more than younger (65, 69-70). The GPs attitudes, beliefs and personalities (50) and fear avoidance (71-72) may also matter. In addition, some GPs feel pressured by patients to issue sick leave certificates (50, 73-74). A Swedish study (70) found that lack of somatic findings in the patient increased the likelihood that the GP would grant sick leave.

During the past decade, several European countries such as Sweden, Denmark and the Netherlands have taken political and structural actions to reduce sick leave rates.

It has been argued that sick leave rates are too high in Norway and higher than in other countries (75), but this argument or statement is debated. Looking at the development of sick leave in Norway from the 1970's to the current position (see Figure 2), no dramatic increase can actually be observed. A review from 2008 (76), comparing sick leave rates in general practice between European countries concluded that sick leave rates are not routinely recorded in all European countries. Comparisons are further complicated by different social security systems and ways of recording the incidence, prevalence, and length of sickness certificates (76).

Several initiatives to reduce the sick leave rates in Norway have been suggested the past few years (75). This has resulted in more attentive follow-up routines, and an increased focus on the use of part-time sick leave as an alternative to full time sick leave (77).

Figure 2: Medically certified and self-certified sick leave per cent, female and male, Norway. 1971 1st quarter -2009 3rd quarter (78)¹.



¹ Numbers from 1971 to 2001 from The Confederation of Norwegian Enterprise (NHO) statistics, while numbers from 2001 are from Statistics Norway (SSB).

2. Overall aims and research questions

The overall aim of this thesis is to contribute to a better understanding of the factors that are important when decisions regarding sick leave are made in general practice in Scandinavia. I will do this by exploring how general practitioners (GPs) diagnose and make sick leave decisions for patients with severe subjective health complaints (SHC).

The thesis has three main research questions:

1. Which diagnoses do general practitioners in Scandinavia give patients with severe subjective health complaints?
2. Do general practitioners in Norway, Sweden and Denmark make similar decisions regarding sick leave for patients with severe subjective health complaints and what factors do they base their decisions on?
3. Which arguments are given by Norwegian general practitioners for declining to participate in a study where sick leave would be decided by randomization?

3. Design, material and methods

Design

We wanted to explore which diagnoses are given by different GPs when they are evaluating identical cases of patients with severe SHC, and what GPs base their sick leave decisions on. To deal with the research questions we conducted two empirical studies. One cross sectional study resulted in two papers; Paper I (the diagnoses study), Paper II (the sick leave decision study), and one qualitative study; Paper III (the research dismissal study). The process underlying the latter of these studies is explained below. By combining different research methods we wanted to achieve a broader understanding of how GPs assess patients with severe SHC and contribute to a more thorough understanding of this kind of clinical work.

By using a *cross sectional design* it was possible to describe which diagnoses GPs chose (Paper I) and what assessment factors GPs based their sick leave decisions on (Paper II) for patients with severe SHC. A short questionnaire, intended to shed light on decisions and dilemmas the GPs face in their daily sick leave routine, was developed (see Appendix 3). Nine video vignettes representing dramatized consultations in general practice provided the context for the questions. Details about data collection are presented below.

The research dismissal study (Paper III) was not planned from the start of the research project that the papers in this thesis originate from. Initially, the intention was to assess the health effects of sick leave by conducting a randomized controlled trial (RCT), where patients with severe SHC would be randomized to sick leave (2-4 weeks) or not (0-5 days). So far, there are only two completed studies where different lengths or types of sick leave have been randomized. Borchgrevink et al (79) succeeded to randomize whiplash patients admitted to the emergency room to either 14 days of sick leave wearing a neck collar, or no neck collar and no sick leave. Viikari-Juntura (80) randomized patients who qualified for full-time sick leave to part-time sick leave or full-time sick leave. In our planned RCT, patients for whom the GP was unsure if sick leave was the right treatment for recovery were to be

recruited for the study. The uncertainty principle was to be followed, meaning that patients could only be entered into the RCT if the responsible GP, and the patient, was sufficiently uncertain if sick leave would be appropriate for the condition the patient presented. However, even though we tried for two years to recruit Norwegian GPs, we failed. We needed the GPs to recruit the patients to the RCT, but most of the GPs we spoke to voiced objections to the feasibility and justifiability to execute such a study. This made us wonder why GPs seemed reluctant to manage sick leave by randomization. We explored their arguments for dismissal in a *qualitative study* where data were collected from the answers of an open-ended question in a web-based questionnaire (Paper III). Contrary to predefined answering alternatives commonly used in questionnaires, open-ended questions may give the participants an opportunity to voice their views more freely on a given topic (81).

Ethics approval

The Norwegian Social Science Data Services approved the cross sectional study that resulted in Paper I and II. The Regional Committee for Medical and Health Research Ethics, Western Norway (REC West) concluded that since the study did not include individual health information, approval was not necessary. The research dismissal study (Paper III) was approved by REC West.

Data collection

The data collected in *the diagnoses* (Paper I) and *the sick leave decision study* (Paper II) are based on nine video vignettes. Initially, 19 authentic consultations of patients visiting their GPs, presenting severe SHC, were videotaped. The patients who were videotaped gave consent for using the material for research and teaching purposes. The research team and a reference group of four GPs selected a purposive sample of nine consultations with variation in the patients' age, gender, and type of complaints. The consultations were then transcribed verbatim, making movie scripts that could be

used for dramatization. Information that could identify the patient was excluded or rewritten. One of the GPs played the role as the GP, and professional actors were recruited for the patient roles. They were instructed to replay the consultations as accurately as possible. The video vignettes, presented in Norwegian with subtitles in Swedish and Danish, included an introduction from the GP, introducing the patients' medical history, previous medical investigations, and the clinical results. The Norwegian, Swedish and Danish languages are closely related and when speaking to each other we can each use our native languages and still be understood. The nine patient's gender, age, demography, 1st complaint mentioned in the consultation, secondary complaints, and the patient's self-assessment of disability are presented in Appendix 4.

In *the diagnoses* study (Paper I), the GPs were requested to provide up to three diagnoses for each patient presented in the video vignettes. The diagnoses were classified according to the ICPC-2 (29), and coded as complaints or symptom diagnoses (A-Z 1-29) or specific disease diagnoses (A-Y 70-99). Norwegian and Danish GPs were familiar with the ICPC-2 coding system (82), but only the Norwegian GPs used this routinely in their daily practice at the time of data collection. Norwegian GPs used the electronic version of the ICPC-2 (ICPC 2-E) (29) in their clinical practice. In Sweden, the GPs used the ICD-10-PHC (33) for classification of diagnoses in their daily clinical practice, but in the diagnoses (Paper I) and the sick leave decision study (Paper II) they were provided with a ICPC-e pager (31).

In the current study, all diagnoses were coded by the GPs using the ICPC-2 pager. In cases where the diagnosis was written only in text without any diagnostic code, such as 'anxiety', or when the text diagnosis and diagnostic codes did not correspond, the researchers categorized the text diagnosis using the Danish ICPC-2 coding system (83). In cases of uncertainty, three of the authors (Holger Ursin (HU), Marianne Rosendal (MR), Erik L. Werner (ELW)), all medical doctors familiar with diagnostic practice, reached a consensus on the most appropriate ICPC-2 diagnosis.

In *the sick leave decision study* (Paper II) the participants were asked to make decisions on sick leave. The sick listing options in the different countries were adjusted to the options in use in 2009-2010 (see Table IV). After making a decision, the GPs were then asked to answer or rate the questions and statements presented in Table V (next page).

Table IV: Sick leave (SL) options in Norway, Sweden and Denmark in 2009-2010

| | | | | | | | |
|----------------|------------|--------------|---------------|------------------|---------------------------|-----------------------------------|-----------------------|
| Norway | 100% SL | Active SL | Partial SL | Pending SL | Rehabilitati on* money | Vocational* rehabilitatio n | Disability pension |
| Sweden | 100% SL | | Partial SL | Preventive SL | | | Permane nt SL |
| Denmark | 100% SL | | Partial SL | | | | |

*In 2011 these two sick leave options were merged and called 'work assessment allowance'.

We used a web-based questionnaire for data collection in *the research dismissal study* (Paper III). The questionnaire was available online for self-recruited participants during the recruitment period (March-April 2010), where information about the study, its purpose and design, including information about confidentiality, and consent was presented. Those who wanted to participate had to actively navigate to an online survey company, Questback™ (84) through a link in the invitation. Anonymity was thereby ensured, and the IP addresses of the GPs were never visible to the researchers. No password or personal identification was asked for. The GPs were asked whether or not they would participate in a study to evaluate the effect of sick listing for selected patients. Those who declined to participate in the RCT were invited to share their arguments in free text within a limit of 4000 characters. Pilot testing of the open-ended request concluded that the following phrasing would effectively prompt arguments for dismissal:

"Describe concrete challenges you will meet if sick listing of your patients should be decided by randomization in a research project".

Table V: Questions and statements in the questionnaire

| Questions and statements | Response categories or answering options | | | | |
|---|---|--------------|-----------|-------------------|------------------|
| From your medical point of view, how long do you think the sick leave period should last? | Up to 1 week | 1-2 weeks | 2-4 weeks | More than 4 weeks | |
| The work situation is the main reason for the patient's complaints | Totally agree | Partly agree | Neutral | Partly disagree | Totally disagree |
| His/her private life is the main reason for the patient's complaints | Totally agree | Partly agree | Neutral | Partly disagree | Totally disagree |
| Medical and health related factors are the main reason for granting sick leave | Totally agree | Partly agree | Neutral | Partly disagree | Totally disagree |
| The patient is not motivated for work | Totally agree | Partly agree | Neutral | Partly disagree | Totally disagree |
| If the patient is not sick listed, the complaints will worsen or slow down the healing | Totally agree | Partly agree | Neutral | Partly disagree | Totally disagree |
| How would you judge the patient's ability to work? | Severely reduced | Very reduced | Reduced | Not very reduced | Not reduced |

When recruitment was exhausted and there were no more incoming responses, the web site with the questionnaire was terminated. By the time of termination, we had received one single positive response for participation in the RCT, and 50 responses from dismissing GPs, presenting their arguments as to why they perceived it as challenging to participate in a research project where the design included randomization of sick leave. The GP who responded positively was included in a pilot study for the RCT. After a one month pilot period the GP had not included any patients because he had not had any patients in his GP practice that fit the inclusion criteria; both the GP and the patient had to be uncertain if sick leave was necessary. The pilot period was then terminated, and the RCT has not yet been conducted.

Sample

Participants for the diagnoses study (Paper I) and *the sick leave decision study* (Paper II) were GPs from Norway, Sweden and Denmark, see Table VI. For practical reasons, recruitment processes varied a little across countries (see below). The most significant difference was that in Norway and Denmark we sponsored the GPs who participated in Continued Medical Education (CME) courses, whereas in Sweden we paid the GPs to participate in their leisure time.

Table VI: Demographic profile of the Scandinavian GPs (N=126) participating in the study. Number, n and per cent in each category.

| | N (%) | | | | | | | |
|-------------------|------------------------|------------------------|------|------------------------|------|-------------------------|------|-----------------|
| | Total N=126 | Norway n=56 | | Sweden N=29 | | Denmark N=41 | | p-value* |
| Female, | 63 (50) | 20 | (36) | 16 | (55) | 27 | (66) | .01 |
| Age, | | | | | | | | .09 |
| ≤40 | 25 (20) | 15 | (27) | 5 | (17) | 5 | (12) | |
| 41-50 | 46 (37) | 21 | (37) | 6 | (21) | 19 | (46) | |
| ≥51 | 54 (43) | 20 | (36) | 17 | (59) | 17 | (41) | |
| GP experience, | | | | | | | | .01 |
| ≤10 | 53 (42) | 21 | (37) | 10 | (34) | 22 | (54) | |
| 11-15 | 25 (20) | 12 | (21) | 4 | (14) | 9 | (22) | |
| ≥16 | 47 (37) | 23 | (41) | 14 | (48) | 10 | (24) | |
| GP specialist | 102 (81) | 36 | (64) | 26 | (90) | 40 | (98) | .00 |
| Other specialties | 16 (13) | 5 | (9) | 11 | (38) | - | | .00 |

*p-value ($p \leq .05$) for between country differences (ANOVA).

In *Norway*, we invited GPs to participate in a 15-hour course, free of charge. The Norwegian Medical Association approved the course, giving 15 points accredited to the GPs' CME score (necessary for obtaining or maintaining status as specialists in general practice). Advertisement was issued on the web based course catalogue of The Norwegian Medical Association, and through an e-mailing service, reaching all GPs in the areas where the courses were offered. Four courses were offered, two in Oslo, one in Bergen, and one in Troms. The video vignettes were presented for the participants (details about this below), and they answered questionnaires before any lectures or discussions were started. Following data collection, the participants were given lectures and group discussions on the theme, which are published elsewhere (50). Fifty-six GPs participated, 20 women and 36 men, (see Table VI previous page).

In *Sweden*, we collaborated with researchers from The Institute of Stress Medicine in Gothenburg, who invited GPs to watch the nine video vignettes and answer questionnaires individually at home or at their office. We used a secure web based system for this data collection and the GPs were reimbursed 500 Euros. The GPs were recruited from different areas in Sweden, mainly the western part. Advertisement was issued in the national journal of The Swedish Medical Association. GPs were also recruited by using the Institute of Stress Medicine website, and in various meetings for GPs, both locally and nationally. Twenty-nine GPs participated, 16 women and 12 men. We missing gender information on one of the GPs (see Table VI).

In *Denmark*, we collaborated with researchers from the Research Unit of General Practice at Aarhus University. GPs participating in CME groups in the Region of Southern Denmark and Central Denmark Region were invited to watch the nine videos and respond to the questionnaires at home, using a secure web based system. Each of them received a total reimbursement of 360 Euros. After they had watched the videos and answered the questionnaires, they participated in a two-hour meeting where cases and clinical issues were discussed. Forty-three GPs participated, but two

unsuccessfully submitted the questionnaires online, resulting in 41 available responses, 27 women and 14 men (see Table VI).

The research dismissal study (Paper III) included a convenience sample of GPs who were unwilling to participate in the planned RCT. These were recruited by inviting GPs from different sources to participate in a RCT, where eligible patients would be randomized to sick leave or not. The invitation held the options of participation ('yes') or dismissal ('no'). GPs, who responded that they would not participate, were requested to present their arguments explaining the reason for their decision. The invitation was published on Eyr, an e-mail discussion list for Norwegian GPs with 1356 subscribing members. We do not know how many of the members actually read the invitation. An additional source of recruitment was 70 GPs who had participated in courses about sick leave assessment in 2009. They received the same invitation by e-mail. Furthermore, the invitation was distributed by e-mail to approximately 85 GPs through the network of researchers associated with Uni Health. In total 50 GPs responded and participated in the study. For demographic profile see Table VII next page.

Table VII: Demographic specification of the study sample (N=50)

| Variable | % of sample (N = 50) | General GP population (N = 4340) * |
|---|---------------------------------|---|
| Gender | | |
| Men | 66 | 62 |
| Women | 34 | 38 |
| Age | | |
| 31-40 | 22 | 29 |
| 41-50 | 26 | 23 |
| 51-60 | 38 | 30 |
| 61 and older | 12 | 13 |
| Missing | 2 | 0 |
| Years since medical degree | | |
| >40 | 2 | 1,6 |
| 40-31 | 22 | 18 |
| 30-21 | 34 | 28 |
| 20-11 | 16 | 22 |
| ≤10 | 26 | 31 |
| Specialist in general practice | | |
| Yes | 70 | 55 |
| No | 30 | 45 |
| Health region | | |
| North | 20 | 11 |
| Middle | 0 | 14 |
| Vest | 28 | 20 |
| South-east | 52 | 55 |

* Personal communication, Anders Taraldset (Head of statistics, The Norwegian Medical Association) 2011.

Analysis

In *the diagnoses study* (Paper I) the primary objective was to find out which ICPC-2 diagnoses GPs in Scandinavia would give patients with severe SHC, and whether there were any differences between the GPs in Norway, Sweden, and Denmark. Our secondary objective was to explore what kind of treatments the GPs suggested for the nine patients presented in the video vignettes.

To explore this, we counted the number of different ICPC-2 diagnoses for each patient. We also organized the primary, secondary, and tertiary diagnoses according to ICPC-2 chapters. For example; A: General and Unspecified comprised these diagnoses: A01 pain general/multiple sites, A04 weakness/tiredness general, A05 feeling ill, A27 fear of other disease NOS, A29 general symptom/complaint/ other, A97 no disease.

The variable ‘multimorbidity’ was computed to see how many GPs acknowledged that these patients have comorbid or multimorbid complaints. This variable was based on the number (%) of GPs that applied primary and secondary diagnoses from different ICPC-2 chapters. Treatments and referrals were also reported in number (%) of GPs suggesting different treatments and referrals. This variable was based on answers written in free text and categorized according to what treatment the GPs suggested.

ANOVA was used to test group differences in demographic variables between the GPs in the three countries; $p \leq .05$ was set as the limit for statistical significance.

It was uncertain whether the difference in the number of participating GPs in the three countries could explain the differences in number of diagnoses between the countries. To check this, a bootstrapping routine (85) was used and generated a thousand replicated data samples based on a random drawing of diagnoses. Using this routine the results remained stable and projected the same differences in number of diagnoses between the countries as in the original data. Predictive Analytics Software PAWS version 18 (86) were used.

For *the sick leave decision study* (Paper II) sick leave was the dependent variable for all analyses. We dichotomised this variable into ‘sick leave no’ (= the patient has to return to work) and ‘sick leave yes’ (=the patient is granted some form of sick leave) (Figure 3 next page).

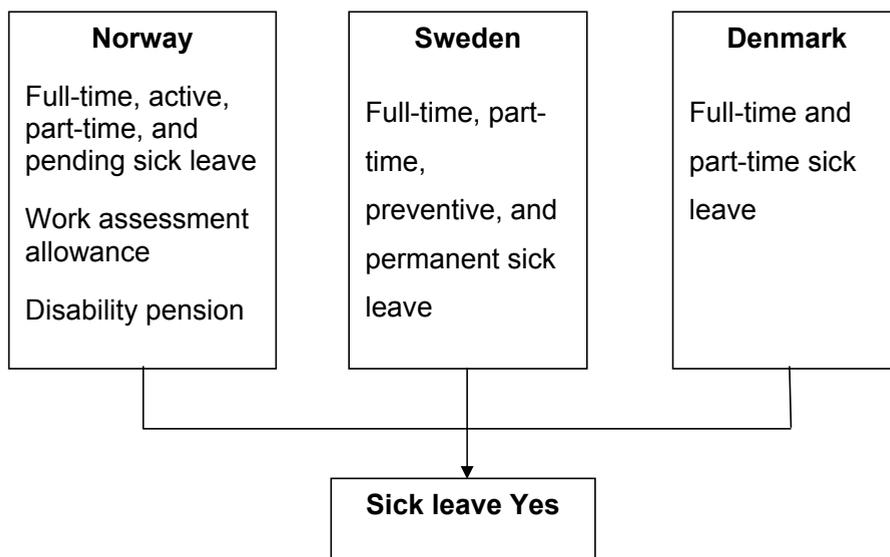


Figure 3: Sickness benefit options available in the different countries underlying the variable “sick leave Yes”

The Kruskal-Wallis Test was used to test variance in sick leave length, and One-way ANOVA was used to test variance in the use of part-time sick leave between the countries. To study the effects of the different variables in the questionnaire on sick leave, we used a mixed effects logistic regression model. In this model, we controlled for each registered patient and each GP. We then added an indicator for the GP and an indicator for ‘patient’ as a random factor. The analyses were initially performed for each country separately. Factors found to be statistically significant ($p \leq 0.05$ (5%)) in the country specific models, were entered into a joint model to test if there were differences in risk factors for granting sick leave between the countries. The analyses were performed using the lme4 library in the statistical package ‘R’ (87). P-values ≤ 0.05 (5%) were considered statistically significant.

The qualitative analysis of *the research dismissal study* (Paper III) was done with systematic text condensation inspired by Giorgi (88) and modified by Malterud (81). This systematic cross-case analysis is data-driven, although supported by theoretical

perspectives, compatible with the editing analysis style presented by Miller & Crabtree (81). The analysis was performed by me (SM) collaborating with my supervisor Kirsti Malterud (KM) through the four steps of Systematic text condensation: (1) Reading all the material to obtain an overall impression and bracketing previous preconceptions; (2) identifying units of meaning and coding for these; (3) condensing and summarizing the contents of each of the coded groups; and (4) generalizing descriptions and concepts (81). All decisions were joint, based on discussions if we initially disagreed. We recorded a decision trail for the whole process, providing a historical document showing the development of the tentative themes, analytical paths, evaluation and adjustments of categories and revisions (81). We dealt with previous preconception by writing into the decision trail (81) what results we expected to find. Although we spent considerable time and effort in designing the open ended question, we critically evaluated which data were suited to illuminate the research question.

In *step 1* all the material was read to obtain an overall impression, trying to pay no attention to our hypotheses and experiences ahead of the study. After step 1 we could for example have two tentative themes; ('reluctant patients' (SM) and 'the patient demands, rights' (KM)). These were then negotiated to a joint tentative theme 'Sick leave is perceived as a human right by the patient when he/she is unable to work'.

In *step 2* we identified units of meaning in the text, representing arguments for why GPs declined to participate in a research project with randomization of sick leave. The tentative themes were then coded and organized in code groups, such as 'Trust – the doctor-patient relationship' and these were used in the subsequent systematization of the units of meaning.

In *step 3* we condensed and summarized the contents of each of the code groups. To highlight the content of the group we then divided each group into subgroups. 'Trust – the doctor-patient relationship' was for example divided into the following subgroups:

- Qualified medical judgement (people are different)

- Trust (doctor-patient relationship)
- Sick leave as a right (there is no alternative for some people)
- Professional authority (the doctor knows best)

From the units of meaning collected in each subgroup, we created a condensate. This condensate is a constructed quote summarizing the essence of the units of meaning from each subgroup in first form. For the subgroup ‘Trust’ under the code ‘Trust – the doctor-patient relationship’ the condensate (my translation from Norwegian) looked like this:

‘My patient-list, based on mutual trust in the doctor-patient relationship, makes it difficult to explain that sick leave will be decided by drawing lots. The individual patient would not understand this. People come to me as a doctor when they realize that they are unable to do their job. Together we evaluate the need for sick leave. If the patient isn’t granted sick leave, he or she will come back the next day for a reassessment, or change GP. Suggesting drawing lots would show that I don’t trust my own, or the patient’s, evaluations of his or her ability to work’.

After writing the condensate we chose a documentary quote from the same subgroup illustrating the condensate in the best possible way. For the subgroup “Trust” we chose the following quote:

“A lot of patients will most probably be angry and feel that I don’t take them seriously if I suggest drawing lots about their sick leave. I want to keep a good relationship with my patients, both on a professional and personal level.”

Step 4 in the analysis according to Systematic text condensation is supposed to generalize descriptions and concepts. Here, we aimed for summarized descriptions of why GPs refused to take part in a research project where sick leave was decided by randomization. Based on the condensates from each subgroup an analytic text in third

person was developed. We also translated the results to English. The subgroup ‘Trust’ was for example elaborated as follows:

‘Almost all the participants voiced that the longstanding relationship with their patients are based on trust and that this relationship would be jeopardised if they suggested that sick listing of the patient would be decided by randomization. They also argued that the patients would not understand, and that the patients see their GP because they are not able to do their work anymore. Some participants mentioned that they discuss the need for sick leave with their patients and together they make a decision. One wrote that if he did not give the patient a sick leave, the patient would come back the next day for a reassessment or just change GP. Several participants wrote that participating in a project like this would show that they did not trust their own nor the patient’s judgement related to the patient’s ability to work. A female GP in her fifties, working in a big city described it like this’:

“A lot of patients will probably be angry and feel they are not taken seriously if I suggest randomization to decide their need for sick leave. I wish to preserve a good relationship with my patients, both on a professional and human level.”

In the process of writing the findings together, the results were re-contextualized and validated against the answers the GPs had given. Codes and subgroups were revised and elaborated, and the subgroup ‘Trust’ was finally presented as a paragraph under the category ‘The doctor-patient relationship could be jeopardized’ in Paper III.

4. Summary of results

Paper I

Maeland S, Werner, E.L, Rosendal M, Jonsdottir I.H, Magnussen L, Ursin H, Eriksen H.R.

Diagnoses of patients with severe subjective health complaints in Scandinavia. A cross sectional study

(Submitted)

Research question 1: Which diagnoses do general practitioners in Scandinavia give patients with severe SHC and what is the subsequent treatment?

A diagnosis is supposed to give the most precise name for a disease, complaint or symptom, lead to treatment and predict prognosis. Diagnostic challenges in patients with severe SHC have been identified. Nine dramatized video vignettes, based on authentic encounters between patients with severe SHC and a GP, were viewed by a convenience sample of self-selected Scandinavian GPs (N = 126) in a cross sectional survey. The main outcome measure was the primary diagnosis classified according to ICPC-2. Analysis demonstrated a substantial variation in ICPC-2 diagnoses for patients with severe SHC among GPs in Scandinavia. P: Psychological, and A: General and Unspecified diagnoses were the most frequently given primary diagnoses. Many GPs also gave secondary and tertiary diagnoses from other ICPC-2 chapters than they had used for the primary diagnosis. Referral to a psychologist was the most frequently suggested treatment, followed by a mix of different treatments. Yet, many of the GPs suggested treating the patients in their own general practice. GPs seem to focus on different particular complaints when diagnosing patients with severe SHC, but still many acknowledge that these patients have multimorbid complaints. Because patients need a diagnosis to be entitled to sickness benefits, it is important to explore if GPs base their sick leave decisions on the diagnosis in patients with severe SHC. This is dealt with in Paper II.

Paper II

Maeland S, Werner, E.L, Rosendal M, Jonsdottir I.H, Magnussen L, Lie S.A, Ursin H, Eriksen H.R.

Sick leave decisions for patients with severe subjective health complaints in general practice - A cross sectional survey in Norway, Sweden and Denmark

(Submitted Scandinavian Journal of Primary Health Care 7.5.2012)

Research question 2: Do general practitioners in Norway, Sweden and Denmark make comparable decisions regarding sick leave for patients with severe subjective health complaints and what factors do they base their decisions on?

Sick leave rates vary between countries. Patients with severe SHC have a substantial amount of long-term sick leave. GPs grant the majority of all medically certified sick leaves. This paper is based on the GPs watching nine dramatized video vignettes in a cross sectional study with Scandinavian GPs (N = 126). Following each vignette, the GPs answered a questionnaire regarding sick leave, reason for the patient's complaints (work situation, private life, medical condition, and motivation for work), work ability and diagnosis. The Kruskal-Wallis Test was used to test variance in sick leave length and One-way ANOVA used to test variance in use of partial sick leave between the countries. To study the effects of the different variables in the questionnaire on sick leave, a mixed effects logistic regression model was used. There were no differences in sick leave decisions between the countries. However a difference within all three countries was observed. Sick leave was granted when the GP assessed the patient's work ability as reduced and that the patient's condition would deteriorate if work was maintained. Diagnosis did not seem to play an important role. Based on the difference in sick leave decisions between GPs within all three countries, we wanted to do a RCT. In the RCT, the effect of sick leave was supposed to be tested. This study was not achievable because GPs did not want to recruit patients. Therefore it is important to explore why GPs' attitudes to decisions regarding sick leave. This is presented in Paper III.

Paper III

Maeland S, Magnussen L.H, Eriksen H.R, Malterud K.

Why are general practitioners reluctant to enrol patients into a RCT on sick leave?

A qualitative study

Scandinavian Journal of Public Health 2011; 39: 888-893

Research question 3: Which arguments are given by Norwegian general practitioners for declining to participate in a study where sick leave would be decided by randomization?

Unsuccessful recruitment of GPs to a randomized controlled trial (RCT) about the effect of sick leave led us to explore the GPs' reasons for reluctance. Individual, written arguments from 50 Norwegian GPs were collected through a web-based, open-ended questionnaire in 2010. The qualitative data were analysed with systematic text condensation. Analysis revealed that the GPs regarded the individual judgment of need for sick leave as a complex task, which requires professional clinical skills that are not suitable for randomization. Their knowledge about their patients' personality, vulnerability, and family situation was assessed as a solid foundation to assess the need for sick leave in each individual case. In addition, the GPs argued that when a patient comes to see their doctor, many expect to be granted sick leave after having presented their complaints. The GPs wrote that it would not be easy to overrule peoples' expectations and deny sick leave, if this was the outcome of randomization. They claimed that the patients often view sick leave as a human and legal right. The GPs also argued that patients would not understand the concept of a RCT if their primary concern was their experienced inability to work. Deciding on sick leave is a joint decision between the GP and the patient, and leaving this to randomization might jeopardize the doctor-patient relationship. GPs were concerned with their patients and their relationship to them, and this makes it difficult to scientifically explore the effects of sick leave.

5. Discussion

Interpretation of results

Diagnostic practice, using a standard diagnostic system (ICPC-2) does not produce reliable diagnoses for patients with severe SHC in general practice in Scandinavia. The GP makes individual assessments of the need for sick leave for each patient, incorporating the patient's vulnerability, personality and family, not necessarily determined by diagnosis. This individual assessment is reflected in the large diversity of diagnoses and insurance benefits made by the GPs. Based on Paper II, the GPs' demographic profile cannot explain the variability of their assessment and choices regarding the patient's need for sick leave. These factors seem to be the same in all three Scandinavian countries, even though there are some differences between GPs within each country. Together, the results from the three studies shed light on the relevance of diagnoses for patients with severe SHC in epidemiology and in sick leave decisions in general. Below, the main findings are discussed, compared to existing research literature within this field.

Diagnosing a patient with severe SHC is a complex clinical skill

Diagnosing disease and illness is a central task for the GP, and naming or labelling is an important step in creating meaning of complaints and symptoms. Yet, diagnoses are socially constructed, reductionistic and only rarely give a complete picture of a patient's condition (38). Diagnostic uncertainty in general practice (35) has been highlighted, and a diagnosis has been reviewed as 'a description of a complex system at a particular point in time' (89).

The results from the diagnoses study (Paper I) shed light on this complexity as it shows that GPs choose different ICPC-2 diagnoses for the same patient with severe SHC even at the exact same point in time. In medicine, objective findings have been thought to discriminate between 'real' and 'unreal' disease (90). However, numerous of severe SHCs, such as chronic pain syndromes, chronic fatigue, tension headaches,

whiplash trauma sequelae, and irritable bowel syndrome, objective findings are lacking. Even though plausible theories can explain the development of these conditions, an understanding of severe SHCs as medically explainable disorders does not seem to be fully implemented in medical theory and practice (91-92).

Peterson et al (34) suggests that objective findings play a modest role in diagnosing patients. History taking is a much more powerful tool in reaching a diagnosis. The skill of history taking, and trust in own judgments increases with the GPs experience (34). Still, a diagnosis does not necessarily lead to therapy and cure in primary care (39) even though this is traditionally what is expected . Diagnosing may be regarded as a process where the GP reach to an understanding with the patient about ‘what is wrong’ and ‘what is to be done’ (93). However, it is hard for the doctor to explain to the patient that the symptoms or complaints they present, do not qualify for a medical diagnosis (39). This may represent a challenge in the clinical encounter between the patient and the GP, because the patient often expects the GP to present an explanation for the patient’s complaints. In such situations, the CATS theory (20) may be helpful in clinical practice to explain how severe and disabling SHC may develop, and to build up a common understanding of what is happening in the body (18). This has been done in a teaching video by Malterud and Prydz (94) where they use sensitization as a psychoneurobiological phenomenon to explain why it can hurt in the lower back, or why the patient is experiencing fatigue, but still does not qualify for a medical diagnosis. Talking to the patient to get his or her experiences is important and valid medical information in the assessment process and to decide if and what diagnosis should apply (34), but it may require special skills when the clinical situation is not sufficiently clear. Malterud (95-96), in her work with women with unspecific health complaints, has developed a strategy for communicating with patients, using key questions to empower patients. Empowering patients with these kinds of complaints has also been emphasized to optimize treatment effects from effective treatments such as cognitive behavioural therapy and antidepressant drugs (10).

The diagnoses study (Paper I) shows that despite identical information, GPs choose to emphasize different complaints and symptoms when diagnosing patients with severe SHC. A high number of different complaints and resulting diagnoses in these types of patients have also been demonstrated by others (97-98). Green and Holden (35) have highlighted the challenge to find the ‘proper’ diagnosis when the condition is unspecific and the patient has a high level of comorbidity. The high number of diagnoses for the nine patients seen in the diagnoses (Paper I) study suggests numerous ways of labelling the same patients where none of the labels could be assessed as wrong or right.

The dualist split of diagnostic categorization may be misleading and arbitrary

While some GPs choose to focus on and attribute the patients’ complaints to psychological factors, others attend to more musculoskeletal, general or unspecified, neurological or social factors. The traditional biomedical habit of attributing and naming these complaints according to anatomical organs has been highlighted as an artefact associated with medical speciality (99). Specialists tend to focus on symptoms pertinent to their speciality (99). GPs are, however, supposed to attend to medical problems beyond anatomical chapters. This may be why their diagnostic labels are so diverse, when the condition in question does not fit nicely into these chapters, probably reflecting the fact that a human being is more than a collection of anatomical chapters. Yet, the GP is usually forced to choose between diagnoses indicating respectively a physical versus a psychological explanation of the patient’s symptoms, thereby enhancing a dualist split.

Somatization disorder is a diagnosis that has been frequently used for these conditions (97). In the diagnoses study (Paper I) however, only 20 % of the diagnoses were somatization disorder (ICPC-2: P75). The inability to talk to the patients in the diagnoses study (Paper I), or the fact that the GPs in the study did not have a personal relationship to the patients may have resulted in a restrictive use of this diagnosis. Burton, however, argues convincingly that although patients with these disorders often

have psychiatric morbidity, they do not have a definite psychological illness and therefore do not fit the criteria for somatization disorder (10). He highlights that multiple factors interact in these patients and illness behaviour patterns evolve within the context of the patient's life (10). An example from clinical practice illustrates this well: A woman age, 69 years comes to see her GP due to dizziness (ICPC: N17) but based on the consultation she ends up with two diagnoses, one for depression (ICPC-2: P03) and one for rheumatoid arthritis (ICPC: L88) (95).

The high prevalence of psychological diagnoses for patients with severe SHC in the diagnoses study (Paper I) has previously been demonstrated in patients with MUS (97). During the past decade there has been an increase in psychological diagnoses in the Norwegian sick leave registers (100) and an increase in the prevalence of psychological sick leave diagnoses in Sweden (101). This is also in line with diagnoses in Norway from 2001-2011 (see Figure 4) where we see a decline in ICPC-2 L: Musculoskeletal diagnoses and a corresponding increase in P: Psychological diagnoses.

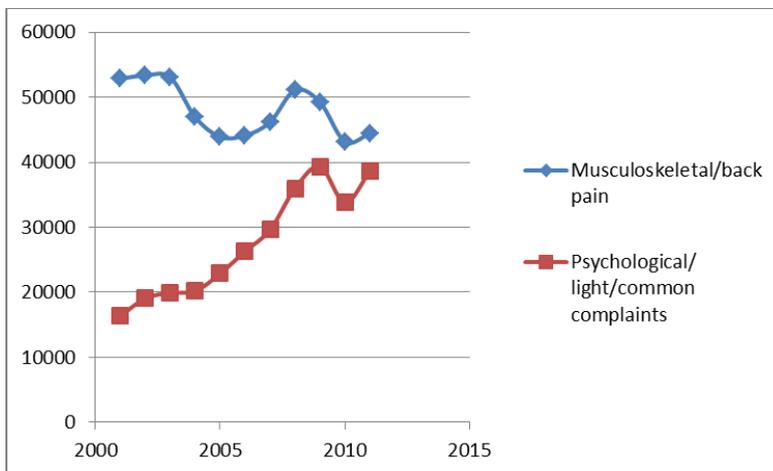


Figure 4: Prevalence and changes in musculoskeletal and psychological sick leave diagnoses in Norway from 2001-2011. Based on numbers from the Norwegian National Insurance Administration (NAV) (102).

Three different hypotheses can explain this shift over time: a) People are more open about their psychological problems and therefore more likely to report them, b) There has been a real increase and an expression of psychosocial strain, or c) There is lower tolerance for stress, which increases complaints and help seeking behaviour (103).

The increased prevalence of psychological diagnoses in the statistics have also been noticed by the Organisation for Economic Co-operation and Development (OECD) (104), expressing a worry that the European populations have a deteriorating psychological health. Ihlebaek et al. (105) however, found that the increased sickness absence rates in Norway could not be explained by an increase in health complaints in the general population in the same period. A more plausible explanation of the shift is that there has been a socio-cultural shift in diagnostic labels, due to diagnoses as socially constructed entities. Changes in attitudes to psychological disorders in the general population affect both patients and doctors (106).

An illustration of this is what has been referred to as the 'Bondevik effect' in Norway: In 1998, the Norwegian prime minister, Kjell Magne Bondevik was sick listed for 3.5 weeks due to a depressive episode. He chose to speak freely about the reason for his absence and in the following years this was frequently debated and covered in the media. With a less stigmatizing attitude to psychological complaints, more patients may dare to disclose such complaints and doctors become more inclined to identify these diagnoses. This is supported by Stansfeld et al (106) who found that due to a greater acceptance, psychological diagnoses are more frequently put on the sickness certificate as reason for reduced work-ability.

The shift in diagnoses supports a hypothesis of 'old wine in new bottles' (99), in the sense that symptoms and complaints remain the same but receive new labels. Ogden (107) highlighted in an editorial in BMJ that doctors often turn to psychology when trying to understand patients and their problems (107). This may in particular be the case in patients where the GP lack objective findings to support, or explain, the symptoms and complaints the patients present. Some researchers (108-109) (49) have suggested that physical symptoms are not the real problem in patients with severe SHC. Instead, psychological problems like anxiety and depression have been

suggested to be the primary complaint and the physical problems come as a consequence (108). Our findings, suggest that such a dualist split, maintaining a linear understanding of disease with physical symptoms coming before or after psychological problems, does not provide an adequate model for severe SHCs.

Sick leave decisions for patients with severe SHC are not determined by the specific diagnoses

Diagnostic uncertainty in patients with musculoskeletal pain has been found to complicate the assessment of functional ability (110). This indicates that there are specific challenges when diagnosis is a prerequisite for sick leave for patients with severe SHC. This has been referred to as ‘the dilemmas of no objective findings’ (50). The lack of objective findings is a fundamental problem that evoke negative feelings in the doctor and it also question if the patient is telling the truth. Objective findings, even if small, ease the justification of issuing sick leave, but are not necessarily taken as ‘proof’ of disease (50). Hence, what is perceived as most problematic in these patients by their doctors is actually the fundament feature of severe SHC. This is one reason why trust in what the patient tells the GP, and the doctor-patient relationship is so important in these cases. ‘*Street level bureaucracy theory*’ describes the dilemmas encountered by professionals in public services (43). Society wants the GPs to respond flexibly to each individual’s unique situation, but at the same time they are expected to act impartially and according to rigid rules (43). Reality is however not so simple, and while GPs may experience that they are able to make a difference to patients’ lives, the advocacy role is not fully compatible with their corporate gate keeper responsibilities (43, 111-112). Inconsistencies and differences between GPs, in issuing sickness certificates have been presented in previous research (113-114). In the results from the sick leave decision study (Paper II) a differences between GPs within all three countries was demonstrated. For all nine patients, 70 % of the GPs agreed whether the patient should be on sick leave or not. It was not possible to pinpoint what separated the 70% from the remaining 30% there are substantial differences in GPs assessment of identical cases. This finding is

supported by the conclusions of a Swedish review on doctors sickness certification practices (115).

In the research dismissal study (Paper III) the GPs argue against randomizing patients for sick leave, by referring to the need of individual assessment. Knowledge of the patients vulnerability, personality and family situation have also been highlighted by others (116). A study by Agledahl suggests that doctors look at, and treat their patients, in a biomedical manner and dehumanize the patients in the encounter (117). Across disciplines, doctors were found to break the patient's story down, concretising the patient's complaints and categorizing them into a medical sense. By doing this, they were able to handle ambiguous realities and establish relevant medical problems. Our results, may actually indicate the contrary, namely that GPs understand these patients in a biopsychosocial paradigm (118). Yet, the GP may not be able to mediate such an understanding sufficiently to the patient in the encounter. Representing 'street level bureaucrats', the GP may experience challenges when rules and regulations, they are supposed to follow, do not comprise the complexity of human life and illness. However, it should be noticed that the legal regulations of the Scandinavian welfare states actually do not limit sick leave benefits to conditions where objective findings can be demonstrated. Functional disability due to disease is the basic ticket to entrance. In the sick leave decision study (Paper II) it was the GPs' assessment of the patients characteristics, not the GPs characteristics, that decided whether the GP granted sick leave or not. The results substantiate the claim that GPs' sick leave decisions are based on clinical skills including an in-depth knowledge about patients. This is supported by a recent large epidemiological study from Norway, where 98% of the unexplained variation in long-term sick leave was attributed to patient factors (66). Only few GP characteristics were associated with the patients' long-term sick leave.

Although we did not explore GPs' perceptions of their gatekeeper role, the results from the research dismissal study (Paper III) may shed light on challenges between the conflict of a gatekeeper role versus a role as the patient's advocate (43). When dilemmas arise, the GP seems to choose the role as the patient's advocate (119-120).

Many Swedish and Norwegian GPs report that they find it problematic to handle the two roles of being the patients advocate versus the gatekeeper of the national social insurance system (111).

Several authors have suggested more and better training in sick listing issues as a way to overcome this (111) (121). Such a strategy is based on the unarticulated assumption that training GPs will result in fewer sick leaves being issued. However, research has demonstrated that training GPs in social insurance medicine may actually increase the rates of sickness certifications issued (122). The results from *the sick leave decision study* (Paper II) did not show any differences in sick leave rates between older and younger GPs. Others however, have found that experienced doctors certify patients' sick leave more often than less experienced doctors (122-123). With increasing experience 'difficult' patients become less difficult to handle (55). Therefore offering GPs training on how to handle these patients and sick leave issues may be appropriate.

Denmark has a different model from Norway and Sweden in the assessment of eligibility for sick leave. *Danish* GPs diagnose the patients, assess their functional ability and work capacity (124). The medical files are then forwarded to a municipal case manager who decides if the patient is entitled to sick leave. In reaching this decision the medical diagnosis has been found to play an important role (124) even though the legislations explicitly focus on assessment of functional ability to be the crucial factor when deciding the need for sick leave. In the *Swedish* system, sick leave is granted by the GP, but length of sick leave is based on what diagnosis the GP give the patient. For patients with severe SHC this may result in different sick leave length depending on which diagnosis the GP gives the patient, and not the patient's complaints or problems. (This is illustrated in Table VIII next page).

Table VIII: Examples from the Swedish diagnose based sick leave recommendations

| Diagnosis | Information | Recommended sick leave |
|--|---|---|
| Acute stress reaction (F43.0)* ICPC-2: P02 | Generally work has positive effect and sick leave should be avoided as long as possible. Work-ability may be completely or partially reduced. | 2-4 weeks |
| Acute lumbago (M54.5)* ICPC-2: L02 or 03 | There is no medical evidence that heavy physical work prolongs healing or results in complications. | Work without lifting, bending, twisting: ≤1 week Work with lifting, bending, twisting: ≤ 2 weeks |

*ICD-10 code

The table is based on data from The National Board of Health and Welfare (Socialstyrelsen) in Sweden (125)

The findings from the sick leave decision study (Paper II) strongly indicate that specific diagnoses play a modest role for the GPs' decisions on sick leave for individual patients, and there are small differences between the three Scandinavian countries. Nevertheless, the research dismissal study (Paper III) suggests that patients with complaints like minor psychological problems, back pain, or shoulder tendonitis would be more easily included in a RCT on sick leave than patients with more distinctive disease diagnoses or conditions judged to be more serious. This indicates that medical diagnosis still plays a role for sick leave decisions in general practice, and that the diagnoses that patients with severe SHC may get, are viewed as more challenging when it comes to sick leave decisions.

Diagnostic labels do, however, seem important in the process of evaluating the patient's right to sickness benefits in real life. In the Swedish system, for example, sick leave length is based on diagnoses (125). Based on the findings from the diagnoses study (Paper I), choosing a diagnosis that is in line with the GPs assessment of need for sick leave, or the patient's demands, seem easy in patients with severe SHC. These patients fit the diagnostic criteria for several diagnoses at the same time. This assumption is further strengthened based on the empirical data from

the sick leave decision study (Paper II). Diagnosis is not the factor that the GPs base their sick leave decisions on.

The sick leave decision (Paper II) and the research dismissal (Paper III) studies show that an individual assessment of the patient's total life-situation is more decisive for sick leave decisions than specific disease diagnoses. Acknowledgement of the multimorbidity in many of these patients may be important in this assessment, as multimorbidity is known to lead to poorer functioning (126). An example from the research dismissal study illustrates this:

"I feel that my in-depth knowledge of the limitations and strengths of my patients, including their socio-psychological level of functioning, gives the best basis for an individual assessment of their need for sick leave. I have known most of my patients for many years."

Capturing and measuring the complexity these patients have, remains a challenge (26) which is confirmed by the findings from the diagnoses study (Paper I). This study indicates that there is no 'proper', or a single correct diagnosis in patients with comorbid complaints. The fact that these patients have many complaints co-occurring, may be the actual health challenge or health burden (24, 26) and the loss of functional ability and work capacity is related to this burden (126).

Being active, and at work while experiencing the symptoms of these complaints, appear to have documented positive effects for these patients (127). Kivimaki and co-workers (128) have shown that for employees with poor health, low levels of medically certified sick leave seem to be associated with positive change in health status. Participation in working life is health promoting in most cases (129). However, long term sick leave is strongly associated with ill health (130) and working while ill, 'sickness presenteeism', may also have serious adverse health effects (131). Based on this we wanted to test the effect of sick leave in the planned RCT.

The reliability of statistics on sick leave diagnoses may be questioned

Despite the focus on functional ability, diagnosis still may play an important role in sick leave issues. The dualistic split in the ICPC-2 diagnostic system may have far reaching consequences. Patients with severe SHC account for about 50% of all long-term sick leaves (59). Our findings have demonstrated how patients with severe SHC involve diagnostic diversity that may be of great importance to epidemiology, epidemiological research and health care planning. Therefore, the reliability of the diagnoses, underlying sick leave epidemiology, deserves attention.

The multimorbid nature of severe SHC also has consequences for the interpretation of epidemiological research findings about patients with these conditions. If a patient is granted sick leave, the doctor has to choose which condition or complaint is put on the sickness certificate as primary diagnosis. This identification of a primary disease or illness diagnosis, is often neither obvious nor useful in primary care (132) especially in patients with severe SHC. Indexing single complaints, for example: ICPC-2: L02 (Back symptom/ complaint), in patients with multimorbidity, results in misleading epidemiology because the patient has many more complaints that are important in clinical care when the GP assess the functional and work-ability and the need for sick leave. The conclusion is that the multimorbidity in patients with severe SHC seems to be neglected in the statistics.

Primary care practice often deals with problems than may never resolve in a definite diagnosis (133). The diagnosis entered into the medical and national statistics form the basis for epidemiological research and political decisions related to public health, preventive health care and rehabilitation. The most important conclusion we may draw from the diagnoses study (Paper I) is that these statistics are unreliable as a description of the medical condition of patients with severe SHC due to the variability of diagnoses between GPs for the same patients. The multimorbidity that we, and others (22, 24, 134-135) have shown is not captured in the ICPC-2 classification system and hence not accounted for in the statistics and epidemiology of reasons for sick leave. This may have consequences for the political strategies that

are used for addressing the health care challenges of the population. Apparently, changes in diagnoses do not necessarily imply that the health complaints in the population are changing. Multifactorial changes in society may lead the GPs to apply different diagnoses. This may be reflected on the sickness certificate. Interpretation of changes in sick leave diagnoses that are based on epidemiological research, (100), as increased mental distress and structural societal changes may therefore be incorrect. Changes in attitudes, and attributions among patients as well as doctors, regarding psychological diagnoses (100) may be a more correct explanation. It appears appropriate to question this increase in mental health problems. Lipsky (43) argues that a general public anxiety and view that there are medical ‘solutions’ to behavioural problems have been advanced by doctors labelling normal characteristics of human nature as illness or disease. The OECD also speaks of a ‘medicalization’ of labour market problems (104) which is in line with Lipsky's theories (43). Our findings suggest that there is a shift in what diagnoses that are entered into the registers and not an actual increase in psychological problems. Still, we cannot dismiss the possibility that there has been a general deterioration in psychological health.

Methodological and ethical considerations

In this section I will look critically at the methodological choices we made to answer the research questions and to explore and test our research hypotheses. I will discuss how our choices have influenced the research process. I will contemplate how we may have influenced the results from the beginning when we wrote the research questions, planned the studies, collected the data, performed the analyses and how we have shared our findings.

External validity – samples and transferability

External validity is an expression for how new knowledge can be transferred onto and into other contexts or populations (81, 136).

We wanted to explore whether, and how, Scandinavian GPs assess patients with severe SHC differently. For this purpose we chose a cross sectional study design for the diagnoses (Paper I) and sick leave decision (Paper II) studies, providing a snapshot of present practice. Such a design does not enable us to assess causality, yet observations in a sample may shed light on phenomena in the population (136). The GPs that we recruited for these studies are not representative for GP populations in Norway, Sweden and Denmark, but comprise *self-recruited convenience samples* of GPs who are probably interested in issues related to severe SHC and sick leave more than average GP. This may limit the external validity of the results.

The *limited number of GPs* from each country adds another concern with regards to the external validity of the diagnoses (Paper I) and the sick leave decision (Paper II) studies. In the diagnoses study (Paper I), this is not a major concern, as the main objective was to investigate whether GPs give the same patient the same or different diagnoses. As the relative small number of different GPs in the study showed a large diagnostic diversity we can assume that this diversity is at least the same in a larger sample. In the sick leave decision study (Paper II), however, the low number (N) is of greater importance because in this study we wanted to explore determining factors for sick leave in patients with severe SHC. Our results would have had more power and generalizability with a larger number of GPs in the study.

The nine patients presented in the video vignettes constitute a *purposive sample of patients* with severe SHC, providing diverse opportunities to explore diagnostic practices. However, the vignette method may make the GP perform ‘doing his or her best’ (65), but not represent ‘real life’ situations where the GP is likely to know the patient (62). In the diagnoses study (Paper I) the GPs were not invited to perform their own history taking skills and this may have influenced their choice of diagnoses

and treatments. Still, we have no reason to believe that the diversity of diagnoses would have been different if GPs were given this opportunity.

The benefit of the *vignette based studies* is that it enables identical information to be provided to all study participants (62). The method with using video vignettes, based on real consultations, reproduced with professional actors playing the patients, as superior compared to written vignettes reflecting authentic consultations. This approach opened up for emotional involvement, which may play an important role in sick leave issues (50).

The GPs that participated in the research dismissal study (Paper III) are a *convenience sample*. Although the demographic profile of the sample was comparable to the Norwegian GP population, it is not representative for Norwegian GPs. However, in qualitative research, external validity is based on factors other than population representativity. Transferability of our findings depends more on factors such as the relevance of the research question in other contexts, what kind of answers we get based on the questions we ask and whether we have asked a sufficient broad range of people that can shed light on the phenomenon we want new knowledge about. The research dismissal study (Paper III) is based on a sample of GPs that took an active standpoint that they did not want to participate in a study where patients are randomized to sick leave. Their arguments provided *information-rich data* containing abundant and diverse accounts of why they were reluctant to randomize patients in a RCT. Together with achieved saturation and the large variability in the GPs demographic profiles, the empirical data contributes to new understanding of the phenomenon (81). It has been argued that the sample should be sufficiently large and varied to elucidate the aim of the study (137) and the outcome of the analyses gave us a broader understanding of why we were not able to recruit GPs to the planned RCT. This is highly relevant in this setting with regards to the external validity of this study (81). To assess why it was unfeasible to conduct the planned RCT was an important task for evaluation of the failed RCT. Alternative assumptions based on our preconceptions regarding explanations on the unfeasibility could have resulted in invalid conclusions that may have leaded us astray.

Internal validity – strengths and limitations related to design

Internal validity depends on whether the choice of methodological instruments adequately sheds light on what we intend to explore. The research method must be appropriate for, and compatible with the phenomenon we want to study (81, 136).

A discussion of the *questionnaires* and *coding tool* applied in the diagnoses (Paper I) and the sick leave decision (Paper II) studies is required. These instruments were chosen to assess how GPs operate the national insurance systems with special focus on patients with severe SHC. One of the main reasons for rejecting a paper for scientific publication is use of unvalidated research instruments (138). There were, however, no available questionnaires previously developed for the purposes of these studies, so a questionnaire intended to incorporate essential elements of the social insurance systems in Norway, Sweden and Denmark had to be developed. The questionnaire was adapted to the specific insurance benefits available, according to country, at the time of data collection.

The cross sectional study (Paper I and Paper II) was explorative and represents something new in trying to disentangle what is behind the numbers in the large epidemiological sick leave studies. The questionnaire was short and simple, and included aspects relevant to a GPs assessment of a patients need for sick leave.

For the diagnoses (Paper I) study there are challenges related to how the data from assessment of nine patients performed by 56 Norwegian, 29 Swedish and 41 Danish GPs should be *analysed and presented*. Descriptive statistics, calculating means and standard deviation (SD) and frequencies of diagnoses for each of the nine patients presented in the video vignettes was used. The aim was to be able to say something about the unknown mean number of diagnoses patients with severe SHC get from GPs in the population. For this comparison to be meaningful, valuable, and credible, it is essential that the same diagnostic criteria are applied (136). With regards to the statements and questions presented in Table V, the internal validity could however be questioned. Here we aimed to assess which factors GPs base their sick leave decisions on. The statements that the GPs were asked to choose among were

developed from several sources: previous sick leave research, clinical experience as a GP, and what GPs thought was the main reason for the patients' complaints. These statements were meant to reflect *common attributions* in sick leave work, for example that some GPs attribute the patients' complaints to health and medical conditions, whereas some attribute the complaints to private life or work situation. The statements were developed by the research group based in Norway, and were not adapted to possible attributions in Sweden and Denmark. This was done due to practical reasons related to comparisons between the countries in the study. We may have included other attributions if we had piloted the questionnaire among more GPs in Norway, Sweden and Denmark. We could also have asked the GPs to write in free text what they attributed the patient's complaints to. This may have given a more valid impression of the GPs assessment, but made the comparisons less feasible in a cross-sectional design.

Observational studies based on register data describe variation in GP practice (66). Such research designs provide valuable and important observations and allow much larger number to be included (136) However, observational research designs do not allow comparison between GPs where the patient is standardized, as the diagnoses (Paper I) and the sick leave decision (Paper II) studies provide.

The patients presented in the vignettes will also have an impact on the internal validity of our findings. The diagnoses (Paper I) and the sick leave decision (Paper II) studies tell us how the GPs diagnosed and made sick leave decisions for these nine patients in particular. They represent *a variety of patients with severe SHC* but are not representative of all patients with severe SHC that visits the GP. Severe SHC involve heterogeneous patient groups and the ways individuals perceive, live and cope with complaints vary greatly (91, 139). Therefore it would be unattainable to get representative samples of patients with severe SHC. Consultations with nineteen patients with severe SHC were video recorded and the research team chose nine patients that gave a comprehensive insight into severe SHC. During the courses we conducted in Norway to collect the data the general feedback from the participating GPs was that they recognized these patients from their clinical practice. The feedback

also confirmed that the cases presented were similar to patient cases in their GP practices. Based on this I would argue that the cases we chose provide a broad range of situations intended to give an insight into the complexity presented by patients with severe SHC.

Aspects of the planned RCT may have been *inadequately explained* or *inadequately read* when we invited GPs to present arguments to decline participation in a randomization procedure in the research dismissal study (Paper III). In particular, we may not have sufficiently stressed that eligible patients for inclusion were patients where both the GP and the patient were unsure if sick leave was the right management for the condition and that we particularly were aiming for patients with severe SHC. This may have threatened the internal validity of the study, as some of the GPs stated that it would be unacceptable to randomize sick leave for patients with diseases like terminal cancer or pneumonia. Patients with such diagnoses were however never intended for the study, and this may not have been sufficiently stressed. It may not have been completely clear which group of patients we intentionally wanted to include in the RCT, as indicated by some GPs claiming that patients with minor psychological problems, back pain, or shoulder tendinitis may be subject for randomization. It is possible that if all the GPs had grasped that these were the patients we wanted to include in the RCT, we might have had more GPs agreeing to participate in the RCT.

In the sick leave decision study (Paper II) we chose a *mixed effect logistic regression model* to see what factors determined the dependent variable 'sick leave'. It may be argued that the design and sample did not hold sufficient power for these analyses; however we also contemplated other ways of analysing data. One option was to present it as case studies. One argument for not doing this was the problem of generalizability. The numerous factors influencing sick leave decisions finally led us to the chosen analytic strategy. We chose to dichotomise the dependent variable by lumping or grouping together all the GPs that indicated that the patient should be on some kind of sick leave. This strategy was discussed, in the research team and could be questioned. It may be argued that if a GP chooses to grant a patient partial or

active sick leave, it is a strong signal that the GP regards contact with the work place as valuable. By lumping all answers indicating any type of sick leave into ‘sick leave yes’ may give a ‘black and white’ impression of situations that are complex and individually based. The *description of the target group of patients in the invitation* may also have influenced our study. When recruiting Norwegian GPs in the diagnoses (Paper I) and the sick leave decision (Paper II) studies we used words such as ‘the difficult patient’ and ‘the patient with no objective findings’. In Denmark the focus was on stress as a possible explanation for why some patients have severe SHC. In Sweden the invitation was distributed from The Institute of Stress Medicine working mainly with stress-related illnesses. This may have influenced who agreed to participate in the study, and they may differ from other GPs, and make different assessments. On the other hand, our intention was to assess if GPs make similar or different diagnosis and sick leave decisions for nine patients with severe SHC. Our results show diversity in assessment between GPs within the countries even though they may all think that these patients are difficult to assess (Norway) or attribute the complaints to stress (Sweden and Denmark). This indicates sufficient internal validity of the methods we applied, although the diversity may have been even larger in a representative sample of GPs in the studies.

We cannot tell how the GPs act towards their own patients in their practices, based on the diagnoses (Paper I) and the sick leave decision (Paper II) studies. The GPs in these studies have provided answers to some questions that are important to get a more comprehensive understanding of the importance of diagnoses for patients with severe SHC in sick leave decisions. The projects’ closeness to everyday clinical practice and the fact that we have asked the GPs how they assess these real, but dramatized patients, support our claim that the results may contribute to an understanding of these processes.

Reflexivity – the impact of the researcher’s position and perspectives regarding interpretation and conclusions

The three studies included in this thesis deal with which diagnoses GPs give patients with severe SHC (Paper I), whether they make comparable sick leave decisions (Paper II), and which arguments GPs give for declining participation in a RCT on sick leave (Paper III). The way we collected the data, chose to analyse it and our perspectives has determined the outcomes of our research. In addition to political, ideological and theoretical issues, it is important to be reflexive about preconceptions and roles as far as possible (81, 140).

If we as researchers identify ourselves strongly with a specific solution or answers, this may lead to inability to see alternatives (81). Undoubtedly, my perspectives have influenced the analyses and results, not only in the qualitative study (Paper III). Yet, as long as my conscious preconceptions, perspectives and background are displayed it, may strengthen the research and counteract an unconscious personal bias. I still want to discuss below, some of the factors that may have influenced these processes, and their potential consequences. Whereas before, I might have shared the lay opinion that GPs willingly grant demanding patients sick leave or the empirical impression that GPs in general perceive patients with severe SHC as difficult, I am now more critical because I am more aware that all discussions and research are situated in social and political contexts (140).

As a physiotherapist, I take up a research position where I in my PhD-project explore how another health profession (GPs) deals with patients with severe SHC. Together with the explorative design of my three studies, all these factors have sharpened my consciousness especially in the processing and interpretation of the empirical data. The fear of drawing wrong conclusions by holding insufficient knowledge of the professional context of the GPs, made me humble towards the results. I have also gained a deeper understanding of the clinical work the GPs do and this has made me more cautious in drawing conclusions when discussing related issues in professional and social settings.

All three studies are based on responses from GPs. To get the GPs to participate in our studies we wrote a text explaining the studies and why we were conducting them. This text reflected our point of views and may have influenced whom we recruited and how they were framed in their responses. In the recruitment process, in the diagnoses (Paper I) and the sick leave decision (Paper II) studies in Denmark for example, we posted an invitation among GPs under the following heading:

CATS – a new CME – about sickness certificates, medically unexplained symptoms and stress

This wording may represent a point of view that is not widely accepted in medical practice (92) and therefore produce a framing effect regarding who participated in the study, how they viewed the patients, and ultimately what diagnosis and sick leave decisions they chose. Based on this, the participating GPs might be pushed by us into a perspective that stress, as a psychological phenomenon, is the reason for, and the primary complaint in patients with severe SHC. I have contemplated whether this may explain the high number of P: Psychological diagnoses in the diagnoses study (Paper I).

To me, the CATS theory (20) has given a deeper understanding of how psychological factors interact with physiological and endocrinological changes, and this have given me a new dimension into understanding human beings and illness. However, I have also struggled with the lay interpretation of the influence of psychological factors – the assumption that if the disease or illness does not show up on x-rays and blood tests, it must be all in your head and not real. Personally I believe that this is one of the core issues that make living with severe SHC, relate to patients with severe SHC, and help patients with severe SHC live a life where the complaints do not rule the daily routines.

In the research dismissal study (Paper III) the researchers had different views on the original RCT. This influenced the invitation and formulation of the open-ended request. Prior to the analyses, KM and I wrote down our preconceptions, operationalized as a list of which results we would expect to arrive at, in the decision trail (81). Bracketing, in the sense of putting all preconceptions aside, is of course an unachievable goal (81). Yet, this procedure made me as a PhD student, feel more secure that our findings were not a result of our preconceptions, since we during analysis could always check out whether we had just followed our own paths. An example was the finding that the GPs did not think that the planned RCT was an achievable design because sick leave is regarded as a human right in Norway. I had previously heard that ‘patients sick list themselves’, but going beyond this lay assumption, and exploring this in the research dismissal study (Paper III) surprised me and resulted in a deeper understanding of the task of granting sick leave in general practice.

Ethics

Politically, it has been stated that sick leave rates in Norway are too high. My thesis is based on research funds from the Norwegian Government through the Research Council of Norway under the Sickness Absence Research Program, which aims to increase knowledge on causes of sickness absence and exclusion from working life. The program is a long-term initiative that will span a period of 10 years (2007-2016), with a total allocation of 310 million NOK (41 million Euros). This funding base, and the preoccupied view that the sick leave rates are too high, influence which research projects are funded and what results are projected. This is an important foundation for the ethical perspectives of my research. ‘*Ethics refers to how values and morals are integrated in the actions and reflections of research*’ (140) (p 1511). If my point of departure was that individuals with severe SHC should not be on sick leave, this might actually conflict *the interest of patients with severe SHC*.

Norwegian media have hinted that individuals on long-term sick leave and disability due to severe SHC are lazy and have low work morals. Some researchers hypothesize that these patients have underlying psychological problems that explains the complaints (108). This is not my view. Our basic understanding and theoretical framework (CATS (20)) can be used in making progress in this complex medical field beyond superficial moralism (94). Olde Hartmann et al (48) point out that GPs recognize the importance of an adequate explanation of the diagnosis of these complaints, but often feel incapable of being able to explain this clearly to patients.

Confidentiality is an important ethical concern in research studies where patient stories are exposed. Making sure that we never exposed the identity of the patients providing the stories that we based our video vignettes on was a major concern in the diagnoses (Paper I) and the sick leave decision (Paper II) studies. We changed year born, number of children, and other recognizable characteristics when we produced the video vignettes with professional actors. The vignettes also include information that the films are dramatizations, to ensure that the actors are not perceived as having the health problems presented. We spent considerable time and effort finding the best and most secure way to save the video vignettes electronically. It had to be secure enough so that nobody unintentionally could access the vignettes, at the same time be available through streaming over the internet when we collected data via Questback™. We managed this by renting a secure web area at the University of Bergen (UIB), Internet Technology Unit. We did not save the vignettes on our personal storage at UIB, and did not experience any episodes that threatened the security of the vignettes.

The REC West deemed the diagnoses (Paper I) and the sick leave decision (Paper II) studies to be outside their mandate for approval because the project did not collect data containing individual health information. Yet, the research group was conscious in our *ethical obligations towards the participating GPs*. The methods we chose cannot be used to evaluate the GPs clinical practice.

6. Conclusion

This thesis shows:

- Diagnosing a patient with severe SHC is a complex clinical skill and different GPs apply a substantial variation of ICPC-2 diagnoses to the same patients. GPs seem to focus on different symptoms and complaints when choosing a diagnosis. Many acknowledge that these patients have multimorbid complaints. The multimorbidity is shown when the GPs apply diagnoses from different ICPC-2 chapters for primary, secondary, and tertiary diagnoses. The dualistic split of diagnostic categorization may be misleading and arbitrary for patients with severe SHC.
- The diagnostic classification and characterization is not useful in sick leave decisions for patients with severe SHC. Sick leave decisions done by GPs in Scandinavia are not determined by specific diagnoses applied to the sickness certificate. Assessment of the patient's work-ability and risk of deterioration if they continue working seem to be more important in the assessment of need for sick leave in patients with severe SHC. GPs may experience a role conflict where he or she is expected to play their role as the gatekeeper of the social security system and their role as the patients' advocate. This may influence clinical practice, since results in this thesis have shown that deciding on sick leave is a joint decision between the GP and the patient. There are no systematic differences in the decisions the GPs in Norway, Sweden and Denmark makes regarding sick leave.
- Since the primary diagnosis on the sick leave certificate forms the basis for national sick leave statistics the variance in these diagnoses affects the reliability of these statistics.

7. Future research

- The multimorbidity in patients with severe SHC is important, since it increases the disease burden in these patients. Many of them experience long-term sick leave and disability. The traditional diagnosis concept in medicine does not sufficiently encompass or measure this important feature. The result is that patients with multimorbidity are indexed with single symptom or disease diagnoses for epidemiological purposes. This represents an important challenge to the doctor, the patient, researchers, and political health care planners. Conceptual development of this complex area must be addressed in future research.
- Further exploration into the dilemmas of the importance of diagnoses, and the gatekeeper versus the patient's advocacy dilemmas, are needed to elucidate the ethical implications around sick leave issues. This is especially important in patients with severe SHC where these dilemmas frequently arise and may result in iatrogenic investigations and treatments.
- The GPs have argued why it is scientifically difficult to study the effects of sick leave. The effect sick leave has on future sick leave remains unexplored. The potential beneficial or harmful effects of sick leave remain an important scientific challenge for the future.

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