# Symptoms as a surmountable challenge

Symptom reporting and self-rated health in the population and in general practice

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"It is devilish to suffer from a pain that is all but nameless. Blessed are they who are stricken only with classifiable diseases! Blessed are the poor, the sick, the crossed in love, for at least other people know what is the matter with them and will listen to their belly-achings with sympathy."

-From Burmese Days, George Orwell

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## ACKNOWLEDGEMENTS

The last 10 years have been anything but boring.

It all started in 2005, when I had signed up to participate in a 30 km trail race for the first time. A few days before the race, I was referred to the hospital because I experienced several symptoms, including dizziness, chest pain and near syncope. It all turned out to be 'just' a sinus tachycardia syndrome, and I was reassured that physical activity was safe. I was in doubt about my safety during physical activity but was sufficiently convinced to get to the starting line, and I finished the race.

Some years later, I had several patients in my practice who had been diagnosed with chronic fatigue syndrome/myalgic enecephalopathy (CFS/ME). I felt inadequate in treating these patients with multi-symptom complaints. A desire to dig deeper into the 'world of symptoms' and to gain a greater understanding of symptoms as a phenomenon led me to research this topic.

Just a few months after I started work on my doctorate, both of my sons, then aged 11 and 12 years, became ill and bedridden with ME. They have been ill and isolated in our house since then. The work with my dissertation has therefore been like a roller coaster and determined by our home situation. In the more difficult periods, it has been hard to remain focused, and the research has felt unimportant and useless compared with life itself.

I express great gratitude to my main supervisor Bård Natvig and my cosupervisor Dag Bruusgaard for their outstanding patience during my long and crooked road to completing my doctorate. Their knowledge and contributions to our discussions have been invaluable, and they have both challenged and encouraged me countless times. Since we first set out together, we have all become grey-haired but hopefully also a little bit wiser.

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Sincere gratitude goes to all the participants in the studies: the general population of Ullensaker and the patients and the GPs in the general practice study. I thank the General Practice Research Fund of the Norwegian Medical Association for financial support.

Loving thanks goes to my husband, Einar, who has been indefatigable in encouraging me to complete my scientific work. He has also taught me how to focus on the bigger issues in life and not to immerse myself in the details. This perspective has been priceless for us to be able continue as a 'normal' family with abnormal challenges. I am forever grateful, Einar, for your support and cheering, and for all our common adventures despite the obstacles along the road.

Our three adolescents, Helene, Martin and Øyvind spice up and bring meaning to my life. They have encouraged me from the very beginning through to the submission of my thesis. I admire their ability to adapt to the sudden shifts in life.

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In parallel with research, running long distances has been my 'medicine'. The goal for most participants in an ultra-marathon is to become a finisher, regardless of the time. I have now crossed the finish line in my doctorate and, along a road that has been covered by symptoms, my sons have gradually begun to regain the hint of a normal life.

## **ABBREVIATIONS**

- ANOVA Analysis of variance
- BDS Bodily distress syndrome
- CFS Chronic fatigue syndrome
- CI Confidence interval
- CNS Central nervous system
- CWP Chronic widespread pain
- FM Fibromyalgia
- GP General practitioner
- ICPC International Classification of Primary Care
- IRR Incidence rate ratio
- IBS Irritable bowel syndrome
- LBP Lower back pain
- ME Myalgic encephalopathy
- MHW Modern health worries
- OR Odds ratio
- MUS Medically unexplained symptoms
- RR Relative risk
- SHC Subjective health complaints inventory
- SNQ Standardized Nordic questionnaire
- SRH Self-rated health
- WHO World Health Organization

## LIST OF PAPERS

The thesis is based on the following three papers, which will later be referred to by their roman numerals:

- Kjeldsberg M, Tschudi-Madsen H, Dalen I, Straand J, Bruusgaard D, Natvig B. Symptom reporting in a general population in Norway: results from the Ullensaker study. Scand J Prim Health Care 2013;31:36–42
- II. Kjeldsberg M, Tschudi-Madsen H, Bruusgaard D, Natvig B. Patients in general practice share a common pattern of symptoms that is partly independent of the diagnosis. Scand J Prim Health Care 2021 Apr 27:1–10. doi: 10.1080/02813432.2021.1913886. Online ahead of print.
- III. Kjeldsberg M, Tschudi-Madsen H, Bruusgaard D, Natvig B. Factors related to self-rated health: a survey among patients and their general practitioners. Resubmitted to Scand J Prim Health Care, 15. May, 2021.

## SUMMARY

Symptoms are the patients' gateway to medical care. Symptom severity, composition and type determine whether a physician is consulted, whether a diagnosis is given and whether further examinations are performed. Symptoms without a clear diagnosis often pose a challenge to patients and physicians.

## Aims and objectives

The first main objective of this thesis was to describe symptom prevalence in a population sample and in general practice patients (Papers I–III). The second objective was to explore self-rated health (SRH) in the population and among general practice patients (Papers I and III). The third objective was to explore factors associated with poor SRH and the report of a high number of symptoms, including diagnoses, unexplained conditions and life stressors, in the population and among general practice patients, (Papers I–III).

## Material and methods

The thesis is based on two materials: The Ullensaker population study and a general practice study.

From the first material, cross-sectional data from the Ullensaker population study 2004 were used (Paper I). A postal questionnaire was sent to seven age cohorts in the population of the municipality of Ullensaker (n = 3325, response rate 54.4%). In paper I, we explored the relationships between the number of symptoms reported and the association with SRH, life-style factors and socio-demographic variables.

The second material was a general practice study performed in 2010–2012 (Papers II and III). Answers to 866 corresponding questionnaires from consecutive adult patients and their 47 general practitioners (GPs) were linked. The patient questionnaire addressed 38 different symptoms

experienced during the previous week, SRH, medically unexplained conditions, life stressors and socio-demographic variables. The GP questionnaire addressed current diagnosis and chronic diagnoses. In Paper II we explored the symptom prevalence among patients and associations with the most prevalent diagnoses. In Paper III we analysed the associations between patients' poor SRH, symptoms, diagnoses, chronic conditions, unexplained conditions and life stressors.

#### Results

In the Ullensaker population study, 91% of respondents reported at least one symptom in the past month, and 47% reported six or more symptoms. Symptom reporting was frequent also among the youngest age group (24–26 years). The highest number of symptoms was found among those with poor SRH, recipients of social security benefits and the unemployed. Women reported a higher mean number of symptoms than men (6.7 vs. 5.1). The strongest association with the number of symptoms was found for SRH, which explained 28% of the variance in the number of symptoms.

In general practice patients, the most commonly reported symptoms were tiredness, lower back pain, headache, neck pain, shoulder pain and sleep problems. The patterns of symptoms reported showed great similarities across age, sex and the most prevalent diagnoses. The mean number of symptoms was highest in patients with asthenia (11.2) and depression/anxiety (10.7), and lowest in patients with hypertension (5.6). The number of symptoms reported was 44% and 23% higher in those with asthenia and depression/anxiety diagnoses, respectively, compared with all other diagnoses. Poor SRH in the past week was reported by 48% of the patients. The strongest association with poor SRH was found for those reporting 12 or more symptoms (odds ratio 16.5, 95% confidence interval 8.9–30.5), those reporting 8–11 symptoms (5.8, 3.3–10.0) and those receiving social security grants (4.2, 2.8–6.4). In a

multivariate model, poor SRH was not significantly associated with the most prevalent diagnoses, the number of prevalent chronic conditions, the reporting life stressors or unexplained conditions.

## Conclusion

In the population study as well as in the general practice setting, the number of symptoms reported by an individual was strongly associated with poor SRH, and this association was partly independent of the diagnosis given. The distribution pattern of symptoms reported showed great similarities across age, sex and the most prevalent diagnoses given by GPs. Based on these findings, we suggest that most patients experience a number of symptoms at any time and that these symptoms are partly independent of the diagnosis given by the doctor. However, the strong association found between number of symptoms and poor SRH indicates it may be important to assess the total symptom load in each individual patient from time to time.

## Main findings

## In the population

- Most people, including young people, reported symptoms in the past month.
- Women reported more symptoms than men.
- People with poor self-rated health reported the highest mean number of symptoms.

## In general practice patients

- The symptom patterns showed great similarities across age, sex and the most prevalent diagnoses.
- Patients reported a certain number of symptoms, which was partly independent of the diagnosis given by the GP.
- Nearly half (48%) of the patients reported poor health in the past week.
- Poor self-rated health was strongly associated with the number of symptoms reported.
- In a multivariate model, poor self-rated health was not associated with prevalent current or chronic diagnoses, life stressors or unexplained conditions.

## NORSK SAMMENDRAG

Symptomer er pasientens inngangsport til medisinsk behandling. Symptomenes alvorlighetsgrad, deres sammensetning og type avgjør hvorvidt lege konsulteres, om en diagnose blir gitt og om videre undersøkelser blir foretatt. Symptomer der en sikker diagnose er vanskelig å gi kan være en utfordring for både pasienter og leger.

## Hovedmål

Dette prosjektet hadde tre hovedmål: Først ønsket vi å beskrive forekomsten av symptomer i en befolkning og i allmennpraksis (Artikkel I–III). Deretter undersøkte vi selvrapportert helse i befolkningen og blant pasienter i allmennpraksis (Artikkel I og III). Videre utforsket vi hvilke faktorer som er assosiert med selvrapportert dårlig helse og rapportering av et høyt antall symptomer, inkludert diagnoser, medisinsk uforklarte tilstander og livshendelser, både i befolkningen og blant pasienter i allmennpraksis, (Artikkel I–III).

## Materiale og metode

Avhandlingen er basert på to materialer; en befolkningsstudie i Ullensaker kommune og en allmennpraksisstudie.

Det første materialet er en befolkningsstudie i Ullensaker kommune fra 2004 (Artikkel I). Et spørreskjema ble sendt pr post til syv alders-kohorter (n=3325, responsrate 54.4%). Vi analyserte sammenhenger mellom antall rapporterte symptomer selvrapportert helse, livsstilsfaktorer og demografiske variabler.

Det andre materialet er en allmennpraksisstudie utført i 2010-2012 (Artikkel II og III). 866 korresponderende svar på spørreskjemaer til voksne pasienter i allmennpraksis og deres 47 fastleger. Pasientskjemaet inneholdt spørsmål om man hadde hatt ett eller flere av 38 symptomer i løpet av den siste uken. I tillegg var det spørsmål om selvrapportert helse, livshendelser, medisinsk uforklarte tilstander og sosiodemografiske variabler. Legene svarte på spørsmål om pasientens kroniske sykdommer og om dagens diagnose.

I artikkel II undersøkte vi forekomsten av symptomer blant pasienter i allmennpraksis, og analyserte sammenhenger mellom symptomer og de hyppigst rapporterte diagnosene. I artikkel III analyserte vi sammenhenger mellom dårlig selvrapportert helse, antall symptomer, diagnoser, kroniske lidelser, medisinsk uforklarte lidelser og livshendelser.

## Resultater

I Ullensakerstudien rapporterte 91% av deltakerne minst ett symptom i løpet av den siste måneden, mens 47% rapporterte seks eller flere symptomer. Også i den yngste aldersgruppen (24–26 år) var det mange som rapporterte mange symptomer. Høyest antall symptomer ble funnet blant de med selvrapportert dårlig helse, mottakere av trygdeytelser og arbeidsledige. Kvinner rapporterte gjennomsnittlig flere symptomer enn menn (6.7 mot 5.1). Den sterkeste assosiasjonen med et høyt antall symptomer var selvrapportert helse, som forklarte 28% av variasjonen i antall symptomer.

Blant pasientene i allmennpraksis var de vanligst rapporterte symptomene; tretthet, korsryggsmerter, hodepine, nakkesmerter, skuldersmerter og søvnproblemer. Det var store likheter i symptommønstre på tvers av alder, kjønn og de vanligste diagnosene. Pasienter med asteni (11.2) og angst/depresjon (10.7) hadde høyest antall symptomer, mens pasienter med hypertensjon hadde lavest (5.6) antall symptomer. Pasienter med asteni og angst/depresjon hadde henholdsvis 44% og 23 % flere symptomer sammenlignet med alle andre diagnoser. Dårlig helse siste uke ble rapportert av 48% av pasientene. Den sterkeste assosiasjonen med dårlig helse var å ha 12 eller flere symptomer (16.5, 8.9–30.5), å ha 8-11 symptomer (5.8, 3.3–10.0) og å motta trygdeytelser (4.2, 2.8–6.4). In en multivariat modell var de vanligste diagnosene, antall kroniske lidelser, livsstressorer og uforklarte lidelser ikke signifikant assosiert med dårlig helse.

## Konklusjon/diskusjon:

Både i befolkningen og i allmennpraksis var det en sterk assosiasjon mellom et høyt antall rapporterte symptomer og selvrapportert dårlig helse, en assosiasjon som var delvis uavhengig av hvilken diagnose som ble gitt. Verken livsstressorer, medisinske uforklarte lidelser eller de fleste av de individuelle symptomene bidro signifikant til pasientenes dårlige selvrapporterte helse. Ut ifra våre funn av sammenfallende symptommønstre på tvers av alder, kjønn, og de vanligst forekommende diagnosene, lanserer vi en teori om at de fleste mennesker til enhver tid har et bakteppe av symptomer, som er delvis uavhengige av diagnosen som blir gitt av allmennpraktikeren. Den sterke sammenhengen mellom antall symptomer og selvrapportert helse indikerer imidlertid at en kartlegging av alle symptomer hos den enkelte pasient fra tid til annen kan være nyttig.

## Hovedfunn

## I befolkningen

- De fleste mennesker rapporterte symptomer i løpet av måned, også unge mennesker.
- Kvinner rapporterte flere symptomer enn menn.
- Personer med selvrapportert dårlig helse hadde høyest gjennomsnittlig antall symptomer.

## Blant pasienter i allmennpraksis

- Symptommønstrene viste store likheter på tvers av kjønn, alder og de mest prevalente diagnosene.
- Pasientene rapporterte et antall symptomer som til dels var uavhengig av diagnosen som ble stilt av allmennlegen.
- Dårlig helse i løpet av siste uke ble rapportert av 48% av pasientene.
- Selvrapportert dårlig helse var sterkt assosiert med antall symptomer som ble rapportert.
- In en multivariat modell var verken de mest prevalente diagnosene, kroniske diagnoser, livsstressorer eller medisinsk uforklarte tilstander assosiert med selvrapportert dårlig helse.

## 1. BACKGROUND

This background chapter first gives an overview of the prevalence of symptoms in the population and in general practice, and describes the definitions of symptoms. This chapter then presents different views on symptoms in general and multiple symptoms in particular, and goes on to provide an overview of the associations between symptoms and self-rated health (SRH). The theoretical context of the thesis and a framework for understanding the results are included.

### 1.1. Symptoms

Symptoms are experienced by most people on a daily basis (1). Despite improved treatment options for a number of diseases, the prevalence of symptoms in the population remains high.

## 1.1.1. Symptom research

Symptoms are the main reason for seeking a consultation in general practice (2). The assessment of symptoms is a key function in general practice. Symptoms assist with diagnosis and is a process that general practitioners (GPs) mostly find meaningful (3). However, many of the symptoms presented in general practice have no clear medical explanation (4), and it can be difficult for the GP to make a diagnosis (2). Unresolved symptoms may present a challenge to both patients and their GP (5). In addition, patients and their GP may have divergent assessments of the severity or the meaning of particular symptoms (6).

Even though it is 'normal' to have one or several symptoms, there is limited knowledge about the whole spectrum of symptoms experienced by patients during the days before consulting their GP. Little is also known about how and why a person proceeds from experiencing a symptom to consulting a GP for that symptom.

The commonly used definitions of symptoms relate symptoms to disorders or diseases (7). The Danish psychiatrist and researcher Fink describes a bodily sensation as a symptom when the patient or the physician perceives the sensation to be to be a sign of disease (8). The symptom researcher and psychiatrist Sharpe defines symptoms as "the patients' subjective experience of changes in his or her body" (9).

These definitions of disease and symptoms are problematic because an individual may have a disease without any symptoms or observable findings, or may experience symptoms without having a disease (10,11). Physician and symptom researcher Kroenke defines symptoms as "a fall from our state of normal functioning" (12). However, a measure of 'normal functioning' is difficult to obtain.

Research on symptomatology has gained increased interest in recent years, partly because of concerns about how different aspects of modern life and new technology can affect health (13,14). Medical research has primarily focused on the management of diseases, improvement of diagnostics and risk factors for future disease. However, research on symptoms is also of significance for several reasons, as detailed below.

In a publication on the strengthening of general practice towards the year 2020, the Norwegian Medical Association stressed the importance of research on symptoms, particularly conditions comprising multiple symptoms (15). Research on symptoms has a strong relevance for general practice, as GPs frequently have consultations with patients presenting with multiple symptoms

or conditions characterized by multiple symptoms. GPs are also in a position to incorporate information about a broad spectrum of symptoms experienced by their patients.

The WONCA Europe research agenda states that the management of unclarified symptoms and signs is a core competency in general practice (16). However, much of the past research done on symptoms has tended to look at symptoms only as early signs of disease.

Almost 20 years ago, Kroenke stated that symptom research is "a fertile field", and argued that more diagnostic information may be collected from the medical history than from the physical examination and supplementary tests (12). General practice is a natural starting point for research on symptoms because the experience of symptoms is the most common reason for seeking medical care (17). A population perspective is also important to research because most symptoms are managed without individuals seeking health care (18).

The symptoms and reasons for consulting a GP in Norway were mapped by Olav Rutle, a pioneer in primary care research, more than 40 years ago (19). The HUNT studies (Health Survey in North-Trøndelag, 1984–86, 1995–97 and 2006–08) (20) and the Ullensaker studies (21) have explored symptoms in the population in Norway.

The Ullensaker population studies were initiated in 1990 by Olav Rutle, Dag Bruusgaard and Inge Nessiøy with the aim of studying musculoskeletal pain symptoms. This questionnaire-based cohort study was performed in Ullensaker municipality, north of Oslo, and the same cohort was followed up in 1990, 1994, 2004 and 2010. The early results from these studies showed that the number of painful sites was an important dimension (21). For example, these studies reported that the prognosis was good in individuals who reported pain at only one site, whereas the prognosis deteriorated markedly with an increasing number of additional pain sites (22-24).

In a follow-up study, the number of pain sites was found to remain stable over time (25). In addition, a high number of pain sites was found to be a strong predictor of the receipt of the disability pension 14 years later (26), which implied that symptom load is a predictor of future disability.

The Ullensaker studies showed further that a high number of musculoskeletal pain symptoms was associated with poor self-rated health (SRH), regardless of the pain site and severity (27). These findings led us to become interested in symptoms in general and to change the study. In 2004, 13 common symptoms were added to the questionnaire, in addition to the 10 musculoskeletal symptoms originally included. Results from this 2004 survey found a strong correlation between number of pain sites and number of other symptoms, and confirmed a strong association between the total number of symptoms reported and functional status (28).

GPs manage symptoms without a disease diagnosis in about one-third of all consultations (2). Symptom research may therefore benefit from including symptoms as a generic phenomenon and not only as a part of classifiable diseases (29).

The International Classification of Primary Care (ICPC) is the most widely used classification system for capturing and ordering clinical information in primary care (30). The ICPC reflects the frequency and distribution of the health problems commonly encountered in primary care. ICPC is divided into 17 chapters according to body system, which represent the localization of the health problem or disease, and each chapter has its own section for symptom diagnoses.

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The ICPC states clearly that a diagnosis may be based on symptom occurrence only, without any pathophysiological findings (17). The ICPC system thus allows for symptoms that do not clearly fit into classifiable disease categories to be given a symptom diagnosis that describes the location or characteristics of the symptom, such as lower back pain (LBP) or asthenia. Symptom syndromes are conditions for which the diagnostic criteria are based on patterns of symptoms; fibromyalgia (FM) is an example (31).

A diagnosis does not require reduced function or illness. For example, risk factors may be used for making the diagnosis of conditions such as hypertension, high cholesterol or high eye pressure. This implies that patients with a diagnosis such as hypertension or well-treated diabetes can be asymptomatic.

The total symptom load in an individual may be indicative of future health status (32). Research based only on symptoms presented in the health-care setting may give an incomplete picture of the occurrence of real symptoms (33). It may therefore be of value to explore all symptoms experienced by patients and not only those symptoms reported during a consultation.

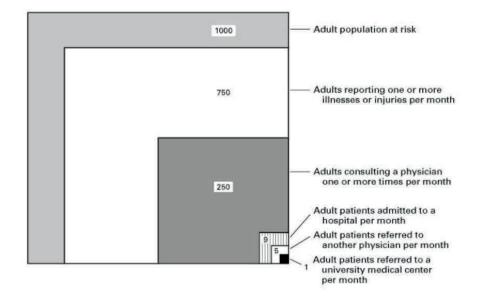
Research on symptom prevalence has, to a large extent, used various measuring instruments (34-36). There is a wide range of symptoms included in symptom checklists, from those including only five symptoms to others with more than 70 symptoms (1,10,36-38). Some studies have focused mainly on symptoms related to specific conditions (39). There is also a large range of time frames used in the different studies, from 1 week to the lifetime (10,18,27,40-42). All of these differences make it difficult to compare symptom prevalence between studies.

## 1.1.2. Symptom reporting

"We must never neglect the patient's own use of his symptoms."

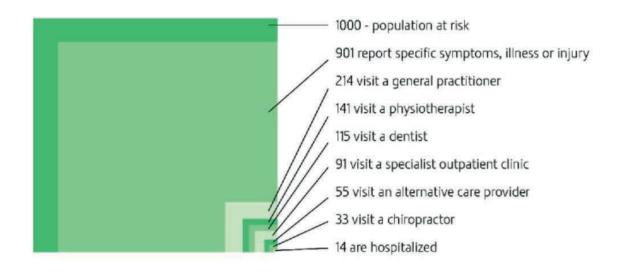
– Alfred Adler, Austrian psychologist, 1870–1937

In a classical paper by White et al. in 1961, the authors estimated that, in a population of 1000 people, 750 will experience some kind of complaint or illness during a month and 250 of them will consult a physician (Figure 1) (43).



*Figure 1.* Monthly prevalence estimates of illness in the community and the roles of physicians, hospitals, and university medical centres in the provision of medical care. White KL et al. The ecology of medical care. N Engl J Med, 1961 (43).

A Norwegian study from 2007–08 reported similar proportions (Figure 2) (44). Among 1000 adult people aged 30 years or more, 901 were found to report health problems or symptoms during a given month. This study reported that, of 1000 people, 214 visited a general practitioner and only 14 were admitted to hospital during the same time period. These findings show that most of the population experience symptoms and, when individuals seek health care, most of the symptoms are handled in general practice.



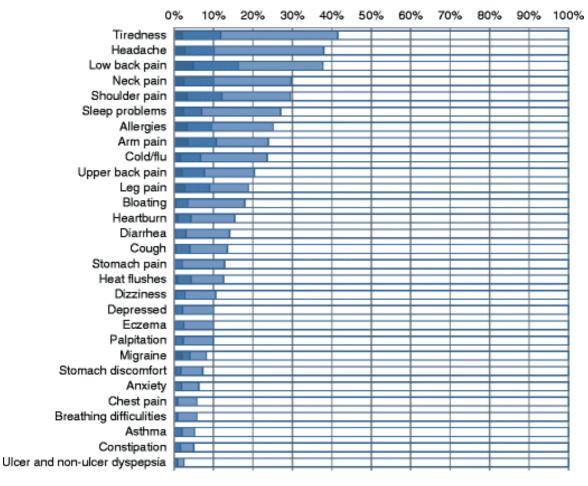
*Figure 2.* Monthly prevalence estimates of self-reported symptoms and illnesses, and use of different health care services for Norwegian persons 30 years and over in 2012. Hansen AH et al. The ecology of medical care in Norway. J Public Health 2012 (44).

In a Norwegian (45) and a Danish population (11), at least one symptom during the past month was reported by 96% and 90%, respectively. In a British study, 90% had experienced some sort of symptom over the past 2 weeks (10). Only a small proportion of the symptoms experienced lead people to seek medical attention (11,46), which suggests that people commonly use self-management for minor ailments such as headache or flu symptoms (10). Symptoms may also be ignored because the patient is well acquainted with the symptoms and these are symptoms that tend to recur over a long period of time, or because the symptoms are assessed by the patient to be of minor importance. GPs may have a different viewpoint because they tend to overestimate to what extent patients will see them for a given symptom (47).

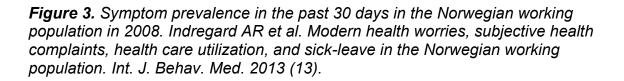
The prevalence of symptoms that are experienced, but not presented to health professionals, are often referred to as the "symptom iceberg" (33). The symptom iceberg metaphor was first described by Last in 1963 and was later operationally defined by Hannay (46). The size of the submerged part of the iceberg relevant to the prevalence of symptoms is mostly unknown.

Women report more symptoms than men (13,18,27,48). However, after controlling for factors such as age, employment status, civil status, educational level and chronic conditions, the sex differences in symptom prevalence seem to be weakened or to disappear (10). For a given symptom, women and men have the same propensity to consult a GP (40,49).

Despite the large differences in the symptom checklists used, many of the same symptoms are found to be the most common in several studies. Among the most frequently reported symptoms are tiredness, LBP, headache, joint pain and sleep problems, both in the population (10,11,45) and in general practice (2,37). A similar symptom distribution has been reported for a Norwegian population study by Indregard et al. in 2008, as shown in Figure 3 (13).



Severe Some A little Not at all



Although tiredness is a frequently reported symptom, serious somatic disease is rarely found in patients with tiredness (50). A prospective study found somatic pathology in only 8% of patients presenting to a GP with a new episode of tiredness or fatigue (51). However, patients in general practice presenting with tiredness are at risk of poor health and reduced function in the future (52). In a study of sick-listed patients with chronic LBP, tiredness was found to be an independent predictor of long-term disability (53). Musculoskeletal symptoms are highly prevalent in the population. At least 75% of adults in Norway experience some sort of musculoskeletal pain during a given month (54). Musculoskeletal disorders are known to "hit most and cost most" (55) and account for about 30% of sickness absence in Norway, according to numbers from the Norwegian Labour and Welfare Administration in 2015 (56).

Musculoskeletal pain often occurs in more than one site at the same time (42,57,58). Patients with LBP have a high prevalence of other pain symptoms (59) such as migraine, sleep problems and depression (60). There is also a risk that localized pain can develop into chronic widespread pain (CWP) (61).

Barsky proposed that with time, as chronic conditions have replaced previously life-threatening conditions, some people may develop a lower threshold for tolerating symptoms along with an increased suspicion that symptoms may be a warning sign of serious disease (62).

The reporting of a high number of symptoms is associated with increased health-care utilization (63), increased health-care costs (64) and increased numbers of sickness certifications (65).

Research on symptoms target mainly specific symptoms. Our approach is to consider symptoms as a phenomenon, in which symptoms exist in a continuum from none to multiple symptoms rather than as single symptoms associated with specific diseases.

In this thesis, symptoms were considered to be *any sensations that an individual finds worth reporting*, although these were limited to a symptom checklist in the data collection for the studies.

"Don't expect cure-care may be sufficient."

– Kirsti Malterud, Norwegian GP and researcher

Both members of the population and patients in the health-care system commonly experience numerous symptoms simultaneously, which is termed multi-symptomatology (66). Individual patients who face multi-symptomatology frequently also report poor SRH (67).

Conditions in which multiple symptoms occur simultaneously are often named by the umbrella term "medically unexplained symptoms" (MUS) (68). Multisymptom conditions are characterized by a high number of symptoms, so far the lack of organic cause for the symptoms (69) and the associated disability (64).

Patients with MUS frequently report more symptoms than those with symptoms explained by disease (34). Our research group has previously found a relationship between the number of symptoms reported and concerns about having a medically unexplained condition in general practice patients (70).

The phenomenon of multi-symptomatology has been known for centuries (71). During the 1880s, "neurasthenia", defined as a weakening of the nervous system, became an increasingly used diagnosis (71). The main symptom of neurasthenia was fatigue, and accompanying symptoms were often headache, indigestion, insomnia, increased sweating, nerve pain, tachycardia and palpitations. Overwork of various kinds was considered to be the most common triggering factor of the symptoms, and psychiatrists suspected that there were psychological causes of the symptoms (72).

In an outbreak in a hospital in Los Angeles in 1934, many patients were affected by a wide range of symptoms, including long-lasting muscle pain, tenderness, weakness, memory problems, difficulty concentrating, sleep disturbances and profound fatigue after physical exertion (73). From the clinical presentation of these patients, it was first suspected that these patients had polio virus, but those inflicted developed no muscle wasting and the disease was initially seen as "atypical poliomyelitis". The term mostly used for this multi-symptom disorder today is chronic fatigue syndrome/myalgic encephalopathy (CFS/ME).

### Terminology used to describe multi-symptom syndrome

Medical specialities have descriptions of multi-symptom syndrome within that discipline, for example, irritable bowel syndrome (IBS) in gastroenterology, CFS/ME in infectious disease and FM in rheumatology (74). The term fibromyalgia was introduced in 1976 as a proxy for a clustering of pain symptoms. The FM criteria have been revised several times (31), and there is a continuous development of the criteria to reflect the current understanding of FM (75).

Over the years, several different terms with different sets of inclusion criteria have been used to categorize simultaneously occurring symptoms for which no clear organic pathophysiology can be demonstrated. Such terms include functional somatic syndrome (76), somatoform disorder (68), complex somatic symptom disorder (68), CWP (23), subjective health complaints (35), medically unexplained physical symptoms (77), bodily distress syndrome (BDS) (78), persistent unexplained physical symptoms (79), and the more recent terms bodily distress disorder (80) and functional somatic syndrome (81). Functional somatic disorder is proposed as a new neutral umbrella term for persistent

symptoms, whose diagnosis does not require psychological criteria to be fulfilled (81). However, the usefulness of new classifications of symptom syndromes in practice remains to be seen.

Questions have been raised whether multi-symptom conditions represent one general condition or if they are separate entities (82). Proponents of a further subgrouping of the conditions are referred to in the literature as "splitters". An example of splitting is the proposal for a further division of FM and CFS into separate subgroups. By contrast, the proponents of a "one syndrome theory", called "lumpers", place more emphasis on commonalities than differences between multi-symptom syndromes (78).

The similarities between the symptom syndromes are illustrated by a substantial degree of overlap in symptoms between FM and IBS, interstitial cystitis, tension headache and temporomandibular joint pain (83); between LBP and CWP (22); and between CFS and FM (84). Fink et al. introduced BDS as a unifying construct for symptom syndromes across medical specialties (78), and the BDS criteria successfully capture 10 diagnostic categories of symptom syndromes within one diagnosis. A review of various symptom syndromes found that the similarities outweighed the differences in the syndromes (74).

There is a lack of agreement about what should be considered unexplained symptoms (85). Several researchers regard MUS as an inappropriate and problematic term (86) because this term simply means the "absence of other explanations". The lack of congruence between disease models and clinical reality regarding MUS may increase the explanatory gap between patients and healthcare professionals (87).

Medically explained and unexplained symptoms are similar in terms of their ability to predict health outcomes and functional status (28,70). It has been

suggested that the concept of MUS should be abandoned and, instead, the focus should be on the total burden of symptoms (88).

In this thesis, the term multi-symptomatology is used to describe conditions with multiple symptoms regardless of whether the symptoms are medically explained or not.

## Explanatory theories

Several theories, which are somewhat controversial and conflicting, have been offered to explain how multi-symptomatology arises.

From the 1900s, the term 'somatization' was used to describe multi-symptom syndromes (89). Somatization was first described by the British physician Thomas Sydenham in the 1600s as a disorder restricted to women with "disturbance and inconsistency both of the mind and the body". In somatization disorder, the physical symptoms are considered to be caused by mental stress (89).

The cognitive activation theory of stress was proposed by Ursin and Eriksen in 2004 (90). This theory suggests that, in the absence of coping as part of the stress response, high levels of psycho-physiological, psycho-endocrine, and psycho-immune arousal or stress may occur. The subsequent prolonged activation of the central nervous system (CNS) is proposed to cause somatic disease, despite the lack of any pathological findings in the CNS.

The biopsychosocial model was introduced to unite the roles of the body and mind in relation to illness (91). However, this approach also causes some problems (92) because psychological factors can always be found in patients if the clinician looks closely enough. The biopsychosocial concept is also frequently perceived as focusing more on the psychosocial and less on the 'bio' aspect, which is assumed to be in the background. Moreover, the term does not include other factors that can influence symptoms such as culture, genetics and epigenetics.

The idea of central sensitization is based on an upregulated response to a normal stimulus and is caused by a hyperactive CNS (83). The central sensitization may be caused by either previous painful insults or neuro-inflammation of the central and peripheral nervous systems (93). Neurophysiological processes in the CNS are involved in the persistence and amplification of multiple symptoms through an increased sensory processing (94).

There is growing evidence that multi-symptom conditions have biomedical correlates. Neuroimaging and other techniques show that multi-symptom disorders such as FM and CFS/ME are accompanied by biological changes (83). Other data suggest that multi-symptom conditions may share some common underlying genetic factors (95). The changes found in the nervous, endocrine and immune systems, which reflect activation of the hypothalamic–pituitary–adrenal axis and inflammation, suggest that adverse life events may also influence health outcomes through changes in biological systems (96).

In recent years, research projects have focused on trying to explain, prevent and treat patients with multi-symptom conditions, but the results so far have been disappointing.

#### Disease hierarchy

A hierarchy of diseases is based on the extent to which symptoms can (or cannot) be readily explained or localized (97). More highly ranked diseases typically have specific clinical findings, which are clearly defined in medical terms and have a high mortality but good treatment options (Figure 4) (98). By contrast, diagnoses such as FM and CFS/ME are among the lowest-ranked disorders (98,99). This hierarchy suggests that diffuse bodily complaints might

be seen as more problematic in medicine than 'pure' somatic disorders and even more than 'pure' psychological disorders (100). **Figure 4.** Prestige rankings of chronic diseases and disabilities. A survey among professionals in the disability field in Norway in 2013–2014. Grue et al. Soc Sci Med 2015 (98).

#	Condition	Mean	Std. dev.
1	Myocardial infarction	7.6	1.6
2	Leukemia	7.4	1.9
2	Brain tumor	7.4	2.0
4	Lung cancer	6.7	2.3
5	Colon cancer	6.4	2.1
6	Pancreatic cancer	6.3	2.3
6	Thyroid cancer	6.3	2,2
6	Ovarian cancer	6.3	2.1
9	Blindness	6.1	2.3
10	Asthma	5.6	1.9
10	Pulmonary embolism	5.6	2.1
12	Multiple sclerosis	5.5	1.7
13	Epilepsy	5.4	1.6
14	Deafness	5.2	2.0
15	Spina bifida	5.1	1.8
16	Arthritis	5.0	1.9
17	Bechterew's disease	4.9	1.9
18	ADHD	4.8	1.9
18	Autism	4.8	1.7
18	AIDS	4.8	2.6
18	Cataract	4.8	2.4
22	Cerebral palsy	4.7	1.9
22	Huntington's disease	4.7	1.9
24	Muscle diseases	4.6	1.8
24	Down syndrome	4.6	2.2
26	Dysmelia	4.5	2.1
26	Anorexia	4.5	2.0
26	Dyslexia	4.5	1.9
29	Psoriasis	4.4	1.8
30	Depression	4.3	2.1
30	Schizophrenia	4.3	2.2
32	Sciatica	4.2	2.2
33	Aphasia	3.9	1.8
33	Myalgic encephalomyelitis	3.9	2.0
35	Anxiety neurosis	3.8	2.0
36	Restricted growth	3.7	1.9
37	Fibromyalgia	3.5	2.0
38	Cirrhosis of the liver	3.3	2.0

Disease and impairment prestige. Rank and mean scores. N = 106.

# 1.1.4. Consultations for symptoms

"The human struggle to live in a gray-scale space where our quest for certainty is central to our psychology, but where uncertainty is rife."

Arabella Simpkin, UK physician and researcher, from "Tolerating uncertainty"

## Health-care-seeking behaviour

The threshold at which a symptom is considered an illness varies greatly and can influence health-care-seeking behaviour. For example, whether a person consults a physician because of a symptom can be affected by the perception of the illness, the symptom attribution and the perceived severity of the symptom.

In recent decades, the media has provided extensive coverage of various health issues, such as "hidden diagnoses", by inviting participants to score their symptoms against checklists. Through its presentation in the media, the derived health information may prompt some people to scrutinize their health and focus on their symptoms and bodily sensations, which may lead them to worry more about their health (101). Furthermore, expanded treatment options may have lowered the limit of tolerance for symptoms and correspondingly increased expectations about the health-service system (102).

We previously reported that almost 40% of general practice patients had considered whether they had experienced an unexplained condition (70). This finding suggests that people may find their own diagnostic explanations when searching for a cause of their experienced symptoms.

A British population study found that only 8% of the symptoms experienced in the past 2 weeks led to a consultation with a GP (103). This finding indicates the vast majority of symptoms are likely to be either managed with self-care or ignored, and that "most individuals do not regard most symptoms as being illnesses, most of the time" (104). Alternatively, people know what a specific symptom represents.

A large Danish population study from 2017 of 100 000 adults found that the decision to contact a GP because of a symptom is strongly influenced by the total symptom burden, its level of influence on daily activities and concern about the symptom (105).

Many patients who visit a physician and come primarily for a health check-up may actually be motivated by specific symptoms or health concerns. In a study in a medical outpatient division, one in three patients had 'hidden agendas' such as health or psychosocial concerns that led them to request a check-up (106). Only a minor part of experienced symptoms are reported to the physician (107), which means that simply counting the symptoms reported to health-care providers will underestimate the actual prevalence of symptoms in a patient population.

#### Patients' perspective

Most patients are highly satisfied with their GP (108). However, when no diagnosis is made and no explanation is given for the symptoms, patients report greater illness worry and dissatisfaction with their GP (2). This may be because GPs tend to underestimate both the number and severity of the symptoms in patients with multiple symptoms (109). When the GP's explanations are at odds with the patient's own thinking, the patient may feel rejected after the encounter (110).

#### GPs' perspective

GPs may see patients who present with multiple symptoms without a clear explanation, as difficult, frustrating and "heart-sinking" (111). The GPs may find it difficult to give such patients a good explanation for their symptoms (112) and may feel helpless and ashamed at their inability to cure the patient or help to resolve the symptoms (113). The GP's desire to reduce diagnostic uncertainty to a minimum may lead to over-investigation of symptoms (114). Conflicting views on the diagnosis and treatment of multi-symptom patients between patients and physicians can influence future management and healthcare utilization (114).

#### Inharmonious consultation behaviour

The relationship between a patient's self-assessment of the severity of symptoms and consultation behaviour is not always harmonious. In a UK study in 1975, Hannay and Maddox explored the "medical symptom iceberg", which they defined as "symptoms without a consultation, in spite of that the patients rated the symptoms as being serious, severe painful or causing disability" (115). They found that 23% of the respondents had at least one symptom they did not seek medical advice for when there seemed to be a good reason for doing so and that 9% consulted because of at least one symptom where there seemed to be no reason based on their own evaluation of the symptom.

## 1.2. Self-rated health

"The most important dimension of health is functional ability to perform those roles that the individual who is being evaluated considers to be important."

-Talcott Parson, American sociologist, 1948.

According to Malterud, knowledge about a patient's own perception of health "belongs to the core content of clinical practice" (116). Insight into how symptoms and diagnoses are related to a patient's SRH is limited.

## 1.2.1. Definitions of health

The definition of health has changed over time. Until the 1940s, health was seen as "a state of normal function that could be disrupted from time to time by disease" (117). In 1948, the World Health Organization (WHO) proposed a definition that aimed higher by linking health to well-being, in which health was defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (118).

To develop consensus for terms and concepts applicable to clinical and preventive medicine, including the term health, a committee was established by the International Epidemiologic Association in 1981. Their definition of health at that time was "A state characterized by anatomic integrity; ability to perform personally valued family, work, and community roles; ability to deal with physical, biological and social stress; a feeling of well-being; and freedom from the risk of disease and untimely death" (117).

During the 1980s, there was a shift from viewing health as a state to thinking of health more as a dynamic, resilient process, in which health represents a "resource for living". In 1984, the WHO revised its definition to the current understanding of health, in which health is understood as, "the extent to which an individual or group is able to realize aspirations and satisfy needs and to change or cope with the environment. Health is a resource for everyday life, not the objective of living; it is a positive concept, emphasizing social and personal resources, as well as physical capacities" (119).

In the 1980s, the sociologist Antonovsky noted the connection between an individual's health and their attitude to life and that attitudes about the ability to cope with stress and unexpected conditions were linked to health. Antonovsky argued that clinicians should focus more on what promotes good health and the ability for coping and well-being. This process was referred to as salutogenesis (derived from the Latin salute, which means health, and genesis, which means origin) in contrast to focusing on pathogenesis (the cause of disease) (120). Antonovsky introduced the Sense of coherence model, which incorporates successful coping with stressors and includes the concepts of comprehensibility, manageability and meaningfulness (121).

In line with this model, Malterud and Hollnagel stated that health may be seen as "the outcome of the balance between symptoms and strains on the one side, and the patient's strong points on the other" (122).

In medicine, disease is often defined as a deviation from a norm, although a precise definition of the distinction between health and sickness is difficult to give (123). The Norwegian researcher of the ethics of science, Hofmann, defines disease, illness and sickness as three different aspects of ill health (124). A diagnostic entity may incorporate any of these concepts. These aspects are reflected in the variation in what conditions people regard as a disease.

The Australian researcher and GP, Sturmberg, believes that health is "an adaptive state, constantly re-establishing itself through interactions between

biological, social, emotional, and cognitive factors in a person's life" (125). He argues further that "over time there has been a migration of the meaning of the concept of 'disease' from initially the subjective dis-ease (dis-ease = absence of ease or elbow room, ease = aise in French = elbow room), towards the objective, disease, where the latter refers to uniquely identifiable biomedical changes". However, clinical practice teaches us that many experiences of 'disease' are not associated with objective abnormality.

### 1.2.2. Perceptions about illness and expectations about health

"It is harder to feel confident about one's health when sensations and dysfunctions one has assumed to be trivial are portrayed as ominous, the herald of some heretofore unrecognized and undiagnosed disease."

– Arthur Barsky, US psychiatrist and researcher

Health is often considered to be the opposite of illness or disease, in the sense that poorer health is related to the number of illnesses or diseases.

However, despite the fact that, in many countries, the health of the population has been improving, as shown by increased life expectancy and improved treatment options for a number of diseases, people report increasing aches and pains and declining satisfaction with their own health (126). This phenomenon is known as *"the paradox of health"*, and was first described by Barsky in 1988 (127).

One possible explanation for this health paradox is that, in a prosperous society, the threshold is lowered about what is called a disease. It is also possible that the increasing commercialization of health, and the media focus

on health risks, contribute to creating a climate of fear of disease and a focus on symptoms (127).

Many patients are concerned that the modern lifestyle may pose a health risk and affect health in a negative way (14). In people reporting modern health worries (MHWs), symptoms and signs of poor SRH are commonly attributed to a variety of environmental factors such as food additives, contaminated water supply, amalgam dental fillings, mould in buildings and radiation from mobile phones (128). The degree of concern is associated with the number of symptoms reported (14). In a study of the Norwegian working population, 96% reported concern involving at least one MHW (13). Those with a high number of MHWs had a doubled risk of reporting a high number of symptoms, as well as increased risk of health-care seeking (129) and sick-leave (13).

Through the interpretation of symptoms as signs of abnormality (101), one could propose a clear link between MHWs and symptom reporting. However, studies of a native population living under primitive conditions have provided an additional view of how symptoms may occur. Individuals living in the jungle in the Philippines (130) and Masai people in rural Kenya (131) are found to have more subjective health complaints than a comparative sample of Norwegians, indicating that symptoms and health complaints cannot be attributed only to consequences of modern civilization.

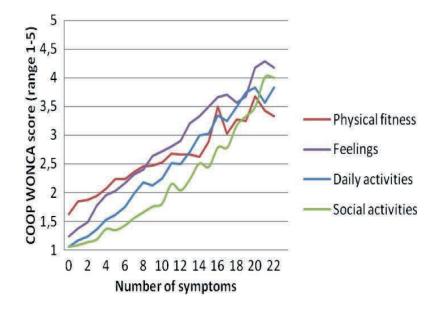
The Norwegian physicians Fugelli and Frich argue that our conceptions of disease and expectations of health may arise "at the crossroads between molecules, thoughts, emotions and values" (132). They emphasize the importance of keeping a watchful eye on social, political and economic factors that may have an interest in moving boundaries and influencing our conceptions about what is sick and what is healthy. This in turn, would influence treatment options and what health services are to be offered.

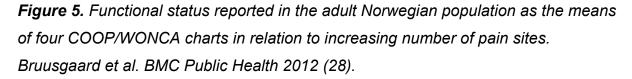
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#### 1.2.3. Factors associated with self-rated health

In the Ullensaker studies, Bruusgaard et al. found an almost linear association between the number of pain sites and reduced function in terms of daily activities, physical fitness, social activities and feelings (Figure 5) (28).

Further, a Danish longitudinal general practice study found that reporting four or more symptoms predicted poor physical and mental health in the patients 2 years later (64).





In addition to the number of symptoms, a longer duration of the symptoms is also associated with a poorer health outcome (133). Kroenke found that 40% of general practice patients who presented with symptoms as the reason for encounter had persistent symptoms at follow up 3 months later. Those with persistent symptoms were more likely to report functional impairment (134). More than 20% of patients with symptoms persistent for more than 5 years reported that the symptoms had considerable impact on their daily life (41). As a widely used measure of SRH, the response to a single-item question is registered: "How would you rate your own health?" Frequently, three to five response categories are provided, ranging from 'poor' to 'excellent' health (135).

Poor SRH is a common finding both among women (136) and old people (137), although the results for gender and age in relation to SRH are complex and somewhat divergent (138).

Further, poor SRH is associated with the following socio-economic factors: being divorced (136), being widowed (139), living alone (136), having a low level of education (140), having a low income (140), being unemployed (126) and being disabled (126).

Life stressors, including negative life events and work stress, are also known contributors to poor SRH (96,139). In addition, genetic factors may contribute to SRH in the individual (141).

A number of studies have shown that poor SRH is a strong predictor of mortality (142,143), morbidity (144), disability (145) and increased health-care utilization (146).

In spite of these known links between SRH and a number of factors, increased emphasis on technological medicine in clinical settings has tended to devalue the importance of what the patients tell. Because of this, clinically useful information may be lost.

# 2. AIMS AND OBJECTIVES OF THE THESIS

One aim of the project was to draw a map of symptomatology and SRH in a general population and among general practice patients. Another aim was to explore factors associated with a high number of reported symptoms and poor SRH in participants in both populations.

The specific objectives were as follows.

- To describe the number of symptoms experienced in an adult population and to explore the relationships between the number of symptoms and demographic factors, lifestyle factors and SRH (Paper I).
- To study the symptoms reported by patients in general practice in terms of both the number of symptoms and types of symptoms, and to explore the relationships between symptoms experienced by patients and the diagnoses given by GPs (Paper II).
- To describe SRH among patients in general practice and to explore possible associations with symptoms, diagnoses, unexplained conditions and life stressors (Paper III).

## Possible implications of this thesis research

Results from this research may lead to increased knowledge about the presence of coexisting, but frequently unmentioned, symptoms in the population and in general practice patients. Further, results from this research may provide insight into which factors may be associated with the reporting of a high number of symptoms and poor SRH by individual patients. Such awareness can be useful for GPs in their clinical work, to better understand patients' needs.

# 3. MATERIAL AND METHODS

# **Design and setting**

The studies in this thesis used data selected from two cross-sectional studies: one an epidemiological study based on data from the Ullensaker population study performed in 2004 (Study A, Paper I) and the other a study of patients and GPs in general practice performed in 2010–2012 (Study B, Papers II and III).

Table 1: Studies and papers of this thesis.

Paper	Setting	Study	Sample included
I	General population	А	Questionnaires completed by 3225 inhabitants
Ш	General practice	В	Questionnaires for 866 linked GPs/patients
	General practice	В	Questionnaires for 866 linked GPs/patients

# 3.1. Paper I – Study A: the Ullensaker population study

# Study design and recruitment to the study

Paper I is based on results from a general population study (Study A). The questionnaire is included in Appendix A.

The Ullensaker study was initiated at the Institute of General Practice in Oslo by Olav Rutle and Dag Bruusgaard in 1990 and was intended primarily to explore the occurrence and distribution of musculoskeletal complaints in age cohorts within an adult population. The study in 1990 and 1994 was initially built around the validated Nordic Questionnaire on Musculoskeletal Complaints (SNQ) (147) and asked about pain or discomfort experienced in the past 7 days in the following 10 areas of the body: head, upper neck, upper back, shoulders, elbows, hands/wrists, lower back, hips, knees, ankles/feet. The response categories were "yes" and "no".

In 2004, a selection of the most common symptoms from the validated Subjective Health Complaints Inventory (SHC) (45) were included in the questionnaire, with the aim of exploring non-musculoskeletal complaints. Out of the 29 symptoms originally included in the SHC, 13 common symptoms based on those not covered by the SNQ were included. The respondents were asked to record whether they had experienced any of the 13 symptoms during the past 30 days and to grade the symptoms into the following categories: "not at all", "a little", "some" and "severe". The symptom variables in Paper I are shown in Table 2.

Six questions about items from the validated COOP-WONCA charts (135) were included in the study in 2004: feelings, daily activities, social activities, physical activities, pain and overall health. The data for physical activities and overall health were used in the analyses in this thesis.

 Table 2: The symptom variables in study A (Paper I).

Pain symptoms in the past 7 days (Standardized Nordic Questionnaire)	Other common symptoms in the past 30 days not included in the SNQ (adapted from the Subjective Health Complaints Inventory)
1. Head	11. Palpitations/extra heart beats
2. Neck	12. Chest pain
3. Shoulders	13. Breathing difficulties
4. Upper back	14. Heartburn
5. Elbows	15. Stomach discomfort
6. Wrists/hands	16. Diarrhoea
7. Lower back	17. Constipation
8. Hips	18. Eczema
9. Knees	19. Tiredness
10. Ankles/feet	20. Dizziness
	21. Anxiety
	22. Depression
	23. Sleep problems

#### Study sample

In 2004, inhabitants from selected birth cohorts in Ullensaker municipality were invited to participate in the study. At that time, there were 23 700 inhabitants of Ullensaker. The new international airport Gardermoen, which opened in 1998, had attracted a younger working population to the area compared with the average Norwegian population.

A postal questionnaire was sent to all inhabitants in seven age groups: 24–26, 34–36, 44–46, 54–56, 64–66, 74–76 and 84–86 years. A postal reminder was

sent after 6–8 weeks. In 2004, 6108 people were contacted, and 3325 returned the questionnaire (response rate 54.4%). Women had a higher response rate than men (59% vs. 45%). Participants with missing data for any of the questions covering symptoms were excluded (n = 98).

### 3.2. Papers II and III – Study B: the general practice study

Papers II and III were based on data from the general practice study (Study B). The questionnaires used in Study B included one questionnaire for patients and one for GPs; these questionnaires are included in Appendices B and C, respectively.

#### Study design and recruitment

Study B was a cross-sectional study that was designed to use patient and GP questionnaires linked by serial numbers. GPs in Oslo and the neighbouring municipalities of Akershus were invited to participate through group meetings required to obtain the specialty of general practice (6–8 GPs in each group).

In these group meetings, the GPs were given a short presentation of the importance of symptom research before they were asked to participate in the study, but the research questions of the study were not mentioned. The GPs were asked to complete a questionnaire for at least 20 consecutive, unselected patients (aged 18 years or more) after a consultation during 1–2 days in regular clinical practice. The GPs were asked to invite the same patients to complete a questionnaire directly following the consultation. The GPs did not have access to the patients' responses and the GP questionnaires were returned separately from the patients' questionnaires. A pilot study was performed before the study to adjust the questionnaires. The data from the

pilot study were not included in the final data material. The data collection period was from June 2010 to January 2012. Patients received written information about the study along with the questionnaire. The patients were informed that returning the questionnaires meant that they agreed to participate in the study.

In the patient questionnaire, a checklist of 38 symptoms was provided (Table 3). This was a newly constructed symptom instrument that included 10 symptoms from the SNQ and all of the non-musculoskeletal complaints from the SHC except asthma, migraine and cold/flu. In addition, the following symptoms, which are commonly reported in other studies, were added to the checklist: cold hands/feet, problems concentrating, memory problems, dry eyes, tinnitus, leg cramps, fasciculation, vomiting, oedema, urinary problems, sight problems and fainting.

All symptoms experienced in the past 7 days as listed in the symptom checklist were to be reported. Any boxes in the symptom checklist left open by the patients were registered as the patient not having the symptom.

SRH was registered by the question from the COOP-WONCA overall health chart, "How would you evaluate your own physical and mental health during the past 7 days?" The response categories were "very good", "good", "average", "poor" and "very poor" (Figure 6).

SNQ	SHC
1. Head	11. Infection
2. Neck	12. Palpitations/extra heart beats
3. Shoulders	13. Chest pain
4. Upper back	14. Breathing difficulties
5. Elbows	15. Heartburn
6. Wrists/hands	16. Constipation
7. Lower back	17. Bowel gas/feeling bloated
8. Hips	18. Diarrhoea
9. Knees	19. Nausea/vomiting
10. Ankles/feet	20. Hot flushes
	21. Cold hands/feet
	22. Problems concentrating
	23. Memory problems
	24. Tiredness
	25. Dizziness
	26. Anxiety
	27. Depression
	28. Sleeping problems
	29. Eczema
	30. Allergies
	31. Urinary problems
	32. Leg cramps
	33. Fasciculation/muscle twitching
	34. Visual impairment
	35. Dry eyes
	36. Oedema/feeling swollen
	37. Tinnitus
	38. Fainting

 Table 3: The 38 symptom variables in Study B (Papers II and III).

*Figure 6.* The dependent variable in Paper III, SRH during the past week, as measured using the overall health chart from the COOP-WONCA.

Very good	۲
Good	8
Average	<b>(</b>
Poor	8
<u>Very poor</u>	۲

How would you evaluate your own physical and mental health during the past seven days?

Patients were asked to record the following socio-demographic variables: sex, age, civil status, educational level and employment status. The questionnaire also asked whether the patients were experiencing or considered they were experiencing one or more of the following unexplained conditions: amalgam poisoning, candida syndrome, electromagnetic hypersensitivity syndrome, FM, CFS/ME, food intolerance, burnout syndrome and IBS. The conditions were not defined further or explained, and no time window was defined; instead, the questionnaire asked about any consideration the participants may have had, in the past and in the present.

The patients were also asked to report any life stressors thought to have a negative impact on their present health with the following question, "In your opinion, have any of the following issues had a negative impact on your present health?" The response categories were work situation, experiences in childhood/adolescence, family issues, economic issues and other serious life events.

In the GP questionnaire, the GPs were asked to record the current main diagnosis (only one) either using the ICPC code or text. The GPs were also asked to answer the following question, "Does the patient today, in addition, have one or more diagnoses within the following categories: coronary heart disease, lung disease, musculoskeletal disorder, endocrine disorder, gastroenterological disease, mental disorder, neurological disease or other?"

The variables used in Papers II and III are listed in Tables 4 and 5.

## Study sample

In total, 66 GPs agreed to participate, 47 of whom returned the questionnaires after one reminder (GP response rate 71.2%). A total of 1024 GP questionnaires and 909 patient questionnaires were returned (patient response rate 89.6%).

Data from both the GP and patient questionnaires were used in Papers II and III. The number of linked questionnaires was 882, of which 866 had complete data and were included in the analyses.

## 3.3. Statistical analysis

The dependent variables analysed in Papers I–III are listed in Table 4, and the independent variables used are listed in Table 5.

Table 4: The dependent variables used in Papers I–III

Paper	Study	Dependent variable	
Ι	А	Number of symptoms (0–23)	
II	В	Number of symptoms (0–38)	
Π	В	Individual symptoms	
Ш	В	Self-rated health	

The two studies operated with different time frames for registering symptoms. In the population study, the time frames were the same as in the original SNQ and SHC instruments, and 7 and 30 days were retained for the registration of symptoms, respectively. In the GP study, the time frame was adjusted to obtain a consistent measure of symptoms experienced in the past 7 days.

The analyses were performed using IBM SPSS Statistics (versions 18 (SPSS Inc, Chicago, IL) and 22 and 26 (IBM Corp., Armonk, NY)), R software version 3.5.2 (2018-12-20) and STATA/SE 16.

Independent variables	Paper I	Paper II	Paper III
Patient questionnaire			
Sex	Х	X	Х
Age	Х	X	Х
Marital status	Х	X	Х
Educational status	Х	Х	Х
Employment status	Х	X	Х
Body mass index	Х		
Smoking	Х		
Physical activity	Х		
Self-rated health	Х		
Number of symptoms	Х	X	Х
Individual symptoms		X	Х
Unexplained conditions			Х
Life stressors			Х
GP questionnaire			
Diagnoses		Х	Х
Chronic conditions		Х	Х

Table 5: The independent variables used in Papers I–III

## Paper I

Table 2 gives an overview of the symptom variables analysed in Paper I.

It is likely that some respondents recorded only positive answers ("yes") to the questions on symptoms but did not answer the questions about symptoms they had not experienced. Therefore, imputation procedures were performed. The imputation procedure assumed that, for the questions left blank, the participant had intended to answer "no" (i.e., the symptom was not present).

This imputation was performed for at least one answer for a total of 21.2% of the respondents. Sensitivity analysis was used to control for these imputations in which all analyses were repeated for non-imputed data. The results did not differ significantly between the analyses with and without imputation.

Given the small number of participants in the two oldest age groups, 74–76 years (n = 155) and 84–86 years (n = 19), these two age groups were pooled in the analysis.

A sum score of symptoms was created (range 0–38) for the number of symptoms, which was the dependent variable. Frequencies and percentages were used to describe the prevalence of the symptoms. The associations between the number of symptoms and the independent variables were identified using the *t* test and analysis of variance (ANOVA). Bivariate and multivariate linear regression analyses were performed to identify the explanatory contributions of the independent variables (listed in Table 5) to the dependent variable (number of symptoms).

#### Papers II and III

Table 3 gives an overview of the symptom variables used and evaluated in Papers II and III. The five most prevalent diagnoses were selected, and the others were clustered into an "other" category, which was used as the reference.

The question on SRH from the COOP-WONCA (Figure 6) was modified from the original time frame of 2 weeks to 1 week to match with the time frame for the symptom checklist. SRH was dichotomized into good (patients reporting very good or good health) and poor (patients reporting average, poor or very poor health). Poor SRH was used as the dependent variable (Paper III). Frequencies and percentages were used to describe the prevalence of the symptoms. Independent *t* test and ANOVA with Tukey's post hoc test were used to compare the mean number of symptoms.

In Paper II, the Poisson regression model was used to obtain estimated incidence rate ratios (IRRs) for the number of symptoms in the past week according to the socio-demographic variables and diagnoses. The associations found (the IRRs) represent the change in the number of symptoms in one group relative to the change in the reference group.

Three separate Poisson regression models were fitted to the data, and the best model was selected by using the Bayesian information criterion.

To explore the probability of having a symptom for a given diagnosis compared with the probability of having the same symptom without having the diagnosis in question, the relative risk (RR) and confidence interval (CI) were estimated for all symptoms. The RR estimates and its 95% CI for the symptoms with significant CIs were presented in a forest plot (Paper II).

In Paper III, two different logistic regression analyses were performed to explore the contributions of the separate individual variables to the binary dependent variable, with poor SRH as the outcome variable. Regression model I was performed with SRH as the dependent variable and with all variables included, and the number of symptoms was treated as a sum variable. Probability curves of reporting poor SRH according to the number of symptoms and the most prevalent diagnoses were obtained from the regression model. Regression model II was performed with SRH as the individual symptoms as the independent variables. The results from the multivariate analyses were reported as odds ratios (ORs) and 95% CIs.

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# 3.4. Ethics and funding

# Ethics

The Ullensaker population study was approved by the Regional Committee for Medical and Health Research Ethics in Norway. The questionnaires registered only sex and year of birth, which meant that the identity of the respondents could not be disclosed. Written information about the study was provided with the questionnaire, and participants were informed that returning the completed questionnaire meant that they consented to participate.

The general practice study was presented to the Regional Committee for Medical and Health Research Ethics in Norway. The committee decided that the project fell outside their remit because of the anonymous data. The study was otherwise performed in accordance with the Code of Ethics of the World Medical Association (Helsinki Declaration). Detailed written information about the study was provided with the questionnaire. Those who returned the questionnaire were considered to have consented to participate in the study.

# Disclosure

The author and the supervisors report no conflict of interests with regard to the Ullensaker study, the general practice study and the content and conclusions of this thesis.

# Funding

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# 4. SUMMARY OF THE RESULTS

## 4.1. Paper I

# Symptom reporting in a general population in Norway: results from the Ullensaker study

Kjeldsberg M, Tschudi-Madsen H, Dalen I, Straand J, Bruusgaard D, Natvig B. Scand J Prim Health Care 2013;31:36–42.

**Aim:** To determine the number of self-reported symptoms experienced in an adult population and their relationship with self-rated health, demographic variables and lifestyle factors.

**Design:** A postal questionnaire addressing 23 different symptoms and health, demographic and lifestyle factors was sent to seven age cohorts in the community of Ullensaker, Norway, in 2004. The study included 3325 participants (participation rate 54.4%).

**Results:** At least one symptom was reported by 91.9% of the participants, 46.7% reported six or more, and 17.3% reported 10 or more symptoms in the past 30 days. Symptom reporting was frequent in all age groups, including young people. Women reported a higher mean number of symptoms than men (6.7 vs. 5.1). Those reporting poor health, receiving social security benefits, being unemployed, with a low educational level or with obesity reported the most symptoms. The percentage of respondents with these characteristics increased almost linearly with an increasing number of symptoms. In an adjusted multivariate model, self-reported overall health explained 28.2% of the variance in the number of symptoms.

**Conclusion:** A large proportion of the Ullensaker population reported a high number of symptoms. The total burden of symptoms was strongly associated with the patients' SRH. A simple method of counting symptoms may be useful for assessing patients in general and patients with multiple symptoms in particular.

## 4.2. Paper II

# Patients in general practice share a common pattern of symptoms, that is partly independent of the diagnosis

Kjeldsberg M, Tschudi-Madsen H, Mdala I, Bruusgaard D, Natvig B. Scand J Prim Health Care 2021 Apr 27:1–10.

**Aim:** To describe self-reported symptoms among patients in general practice and to explore the relationships between symptoms experienced by patients and diagnoses given by general practitioners (GPs).

**Design:** Questionnaires on 38 self-reported symptoms during the past 7 days were completed by 1024 patients, and their 47 GPs answered a corresponding questionnaire. This study included 866 patient–doctor-linked answers (overall response rate 84.6%).

**Results:** The most frequently reported symptoms were tiredness (46%), lower back pain (43%), neck pain (41%), headache (39%), shoulder pain (36%) and sleep problems (35%). Women had significantly higher prevalence rates than men for 16 of the 38 symptoms (p < 0.05). The mean number of symptoms was 7.5 (range 0–32), (women 8.1, men 6.5) (p < 0.05). A regression model showed that patients who received social security grants had 59% more symptoms than those who were employed. Patients with asthenia and depression/anxiety had 44% and 23% more symptoms, respectively, than

those with all other diagnoses. The prevalence rates of the symptoms showed similar patterns across the five most prevalent diagnoses.

**Conclusion:** Patients in general practice report a number of symptoms. They also share a common pattern of reported symptoms, which appear to be partly independent of the diagnosis given by the GP. These findings suggest that symptoms are not necessarily an indication of disease.

#### 4.3. Paper III

# Factors related to self-rated health: a survey among patients and their general practitioners

Kjeldsberg M, Tschudi-Madsen H, Bruusgaard D, Natvig B. Resubmitted to Scand J Prim Health Care, 15.May, 2021.

**Aim:** To explore associations between patients' self-rated health (SRH) and symptoms, diagnoses, chronic conditions, unexplained conditions and life stressors.

**Design:** 866 patients in general practice completed questionnaires addressing 38 common symptoms and SRH experienced in the past week. SRH was measured with the COOP-WONCA overall health chart, and dichotomized into good/poor SRH. Corresponding questionnaires were completed by the patients' 47 GPs.

**Results:** Poor SRH in the past week was reported by 48% of the patients. Women, middle-aged, recipients of social security benefits, patients diagnosed with asthenia, lower back pain and depression, as well as patients with reported life stressors and unexplained conditions had a higher prevalence of poor SRH. The likelihood of reporting poor SRH increased linearly with an increasing number of symptoms. The probability of reporting poor SRH increased with increasing number of symptoms for the most prevalent diagnoses. In a multivariate analysis, only number of symptoms, being a recipient of social security benefits and being retired were associated with poor SRH.

**Conclusion:** Poor SRH was strongly associated with the number of symptoms reported, partly independent of the diagnoses given by the GP. This result supports our previous findings of a strong association between number of symptoms, health and function. The symptom burden thus appears to be an important factor for SRH in GP patients. Future approaches to study SRH among patients in general practice might benefit from including a broad spectrum of patient-reported symptoms.

# 5. DISCUSSION OF THE METHODOLOGY

#### 5.1. Design

The data used in all three papers were cross-sectional. This design allowed the assessment of the associations between multiple variables, as intended in the two descriptive, explorative studies (Studies A and B). All data relied on self-report and were collected from questionnaires, which were sent by post (Study A, Paper I) or handed out during consultations in general practice (Study B, Papers II and III).

#### 5.2. Study sample

In Paper I, only data from the Ullensaker population study conducted in 2004 (Study A) were used. The study had a large sample size of 3325 respondents and a fairly good response rate of 54%. The response rate was lower in 2004 than in the two previous Ullensaker studies from 1990 (68%) and 1994 (63%), a decline that follows general trends in response rates in surveys in the past decades (10). Postal questionnaires, which were used in this study, provide an inexpensive method to study a large population, although response rates to such surveys may be low in general.

In Papers II and III, data from the general practice study (Study B) were used. A general practice setting was chosen because of our interest as GPs and because patients with multiple symptoms consult primarily GPs. This doctor– patient-linked approach allowed the comparison of responses of both GPs and patients. In total, 1024 questionnaire pairs were distributed, 909 patient questionnaires were returned, and 882 questionnaires had matched responses for GPs and their patients. Of these questionnaires, 866 had complete data and were included in the analyses, giving an overall response rate of 84.6%.

The included GPs came from urban and suburban districts of southern Norway. It is unknown if the results would have been different if GPs and patients from rural parts of Norway had also been included.

The recruitment of GPs was time consuming because participation in studies implies extra workload for the GPs without compensation. Consequently, the data collection for Study B took place over a long period of time; June 2010 to January 2012. The GPs communicated that lack of time and capacity were the main reasons for not participating. At the time of the study, Norwegian GPs were not enrolled in research networks, which might have facilitated the recruitment.

It is unlikely that the long inclusion period affected the results much because symptom reporting is known to be stable over time (41). For the same reason, the age of the data is unlikely to have affected the results.

#### 5.3. The questionnaires

### The population study – Study A

Many different questionnaires can be used to map the occurrence of symptoms. There is also a wide range in the number and type of symptoms included in the various symptom lists used. This generally poses a major problem in symptom research and makes it difficult to compare results across different studies.

The first two of the Ullensaker surveys (1990, 1994) focused primarily on musculoskeletal pain sites, using the SNQ as a way to identify pain sites. The

rationale for using the SNQ in 2004 is that the number of musculoskeletal symptoms had been explored extensively in the Ullensaker study, which prompted the use of the same instrument in this study to maintain the longitudinal data. The SNQ was modified in all three Ullensaker surveys by including 'head' as the 10<sup>th</sup> body region.

Acquired knowledge at that time showed that the total burden of symptoms, beyond musculoskeletal pain symptoms, can provide important information about health outcomes. Therefore, a modified and shortened version of the SHC was added to the questionnaire in 2004.

To avoid repeating questions about pain symptoms, questions about pain symptoms from the SHC that were included in the SNQ were omitted. Asthma, migraine, allergy and flu were omitted because, in our opinion, they are diseases and not symptoms. Asthma and migraine are included as "breathing difficulties" and "headache", respectively, in the questionnaire. To avoid the predominance of gastrointestinal symptoms, the number of symptoms was reduced from the original seven to four: heartburn, diarrhoea, constipation and stomach discomfort were retained. Because the main focus of Paper I was the number of symptoms and not the individual symptoms; this adjustment is not considered to be important.

The questionnaire also included symptoms that are likely to be transient and minimally bothersome, and therefore may not have been mentioned by patients in their consultations. The rationale behind the choice to explore the total symptom load was that all degrees of severity of symptoms are known to be important for health and function (28). A description of the prevalence of symptoms in the population and in patients consulting with GPs may provide insight into the whole spectrum of symptoms, from normal everyday complaints to symptoms that may be indicative of severe disease.

The use of time windows of 7 days in the SNQ and 30 days in the modified SHC is a constraint that might have influenced the results because there was no consistent measurement of the number of symptoms for a defined time period. Given that the main focus was on associations, it is likely that the different time frames would have underestimated rather than overestimated the associations. We presume that this mismatch did not greatly affect the strong associations or hamper the conclusions. However, it is a limitation to consider when interpreting the results.

## The GP study – Study B

The symptom checklist comprised 38 symptoms (Study B) and was constructed from the SNQ and SHC with the addition of several other common symptoms. The time frame was adjusted to 7 days for all symptoms in the checklist to provide a consistent time frame for all symptoms.

The approach in this thesis research was descriptive and explorative. A long list of symptoms may be useful for capturing more of the symptom variety. However, extensive lists of symptoms have been criticized for being too time consuming and complex, which leads to low response rates.

A validated symptom list could have been chosen instead of designing our own descriptive instrument used in this thesis research. One reason why a validated list was not used is that our research on symptoms has evolved over a long time period and because of the wish to be able to link results to our previous studies. We also wished to include both somatic and mental symptoms, while many of the existing instruments focus on somatic symptoms only (148). For example, the Patient Health Questionnaire-15, which is based on the 15 most common symptoms presented in general practice, is brief and is considered to have a high clinical utility, but it does not include any mental symptoms (34).

The selection of symptoms might also be questioned. Some symptoms may have been excluded and others included, and it may not seem logical that all symptoms should count as one item. However, we wished to include all symptoms experienced, even minor symptoms, and it is difficult to make a theoretical weighting of individual symptoms.

We could have included a grading of the intensity of the symptoms. Because we wanted to map a long list of symptoms and it would have been time consuming to answer questions about intensity for every symptom, the intensity of the symptoms was not considered. In addition, our previous research has shown that the total symptom load, including even minor symptoms considered to be less bothersome, is important for functional ability and SRH (28).

Check boxes in the symptom checklist left open by the patients were registered as indicating the patient did not have the symptom in question. This has probably led to underestimation of the number of symptoms because some patients may have forgotten to tick some of the boxes. This may, however, be a limitation of the studies that the patient questionnaire did not include the opportunity to tick yes or no in the symptom checklist, but only yes.

The time frame of the COOP-WONCA overall health chart was modified from the original 14 days to 7 days in Study B to match with the symptom list. However, this modification is unlikely to have affected the results much.

To measure SRH, a single question on overall health with a five-response option scale, ranging from very good to very poor health, was used. The most commonly used SRH instruments use single-question scales in which the patients rate their own health from excellent to poor on a 3–5-point scale (149). However, with the five-response version of instruments to rate SRH, there is great variation in the labelling of the different categories. For example, the middle category may be labelled "good" (150), "fair" (151), "average" (152), "moderate" (153), "neither good nor bad" (137) or "all right" (142). In addition, many other instruments are used to measure SRH, and these have wider a diversity in both response options and in the labelling of the response categories.

The overall health dimension of the 36-item Short Form Health Survey questionnaire (154) uses five categories from excellent to poor health (1–5). The QLQ-30 quality of life questionnaire (149) uses a seven-point scale from very poor to excellent (1–7), and the Euro Qual-5D (155) uses a visual analogue scale from the worst to the best imaginable health state (0–100). Some studies use a Likert scale with response categories from 1 (very poor) to 8 (very good) (156).

The different SRH instruments are highly correlated with each other, and it is difficult to decide which version is superior. However, both the WHO (157) and the European Network for the Calculation of Health Expectancies 2 group(158) recommend a five-option version of the SRH question.

Different studies have used different methods for pooling the SRH categories. In this thesis, the SRH results were pooled into good (very good + good) and poor (average + poor + very poor) SRH. When the five-item SRH is used as a dichotomized variable, the middle category is pooled with good health in some studies (67), with poor health in others (151), and retained as a separate category in other studies (150). Because the middle response category can make up 30–40% of the responses (150), different methods for pooling may have a marked effect on the prevalence rates and should be considered when interpreting the results. The high prevalence of poor health in the thesis studies probably reflects the choice to pool average with poor and very poor SRH.

An individual's SRH can be regarded either as a spontaneous assessment based on one's present state of wellness or illness, or as a more stable concept of health based on an individual's prior beliefs of being a healthy or unhealthy person. Longitudinal studies have indicated that SRH is best understood as an enduring self-concept (159,160), and the short time frame chosen for registration of SRH in these thesis studies probably had a minor impact on the results.

### 5.4. Statistical analyses

In Paper II, Poisson regression was considered to be the best approach for analysing the number of symptoms as the outcome variable. Poisson regression is considered to be more appropriate for analysing count variables than ordinary regression models because count variables typically have many low count values, skewed distributions and a large variability for prevalence within each of the variables. Using linear regression for count variables may create problems because the assumptions may not be met and bias may be introduced (161). The count variable denoting the number of symptoms was positively skewed with possibilities of zero counts for patients who did not have a particular symptom. Therefore, it is more likely that applying an ordinary linear regression model may have produced negative predicted values for the number of symptoms, which intuitively does not make sense. After the validity of the model was checked, the data suggested that the Poisson regression was an adequate model.

Because of the low prevalence of each diagnosis registered by the GPs, we chose to limit the analyses to explore the five most prevalent diagnoses

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(Papers II and III). However, the low prevalence rates for the individual diagnoses is a weakness that prevents the drawing of firm conclusions about the associations between the five selected diagnoses and the other variables.

To explore the symptom patterns in the selected diagnoses, RRs were used to estimate the effects for all symptoms. The choice of the RR over the OR was based on the assumption that the prevalence of the symptoms was high (>10%).

In Paper II, the RR was used as a descriptive statistic to describe associations with the dichotomous outcome. The RR is an estimation of the probability of having a symptom given a diagnosis, divided by the probability of having the same symptom if the diagnosis is not given (reference). Because the prevalence of symptoms and not the outcome of an event or intervention was measured, the RR was considered to be a well-chosen estimate of the effects.

It is a common practice to model associations with a dichotomous outcome using binary logistic regression models, compute adjusted ORs and interpret the estimates as if they are RRs. However, the argument for interpreting the ORs as RRs holds true only in cases where the outcome is rare (prevalence  $\leq$ 10%). With prevalence rates >10%, ORs tend to overestimate substantially the RRs for common outcomes.

In Paper III, a binary logistic regression model was applied to the dichotomous outcome variable. The main objective was to explore SRH according to a number of variables, including all of the individual symptoms. Because variables with a potentially low number of respondents in each category were included, dichotomization of the dependent variable was considered to be the best solution. However, dichotomization of the dependent variable may result in loss of information.

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# 5.5. Validity and reliability

# **Symptoms**

The validity of a research instrument can be defined as the degree to which the instrument measures what it is intended to measure, and the term has various subtypes.

When a research instrument has "been satisfactorily tested repeatedly in the populations for which it was designed", it is defined as valid (*internal validity*) (162). The symptom list used in our studies had not been validated, but was derived from a combination of the SHC and SNQ, whose validity has been established in previous research (35,147). The head was added as a 10<sup>th</sup> body region in the SNQ, and symptoms of musculoskeletal pain included in the SNQ were omitted in the modified version of the SHC used in this thesis research. Neither of these alterations are likely to have affected the validity of the instrument.

Reliability is defined as achieving consistent results over time given that the same methods and the same conditions are used. The SNQ and SHC have also been found to have an acceptable reliability (35,147).

*External validity* refers to the generalizability of results beyond the study population in question (163). Because the results in both studies were based on self-reported symptoms and the GP study was based on symptoms reported by consecutive unselected patients, we believe the study has some external validity for other populations and GP settings.

*Predictive validity* refers to whether the instrument can predict future outcomes in expected directions (163). Both the SNQ and SHC have been shown to have satisfactory predictive validity in previous research. An instrument used to measure symptoms should not overlap with instruments constructed to measure other variables. This is the criterion needed to ensure *discriminant* validity (163). Discriminant validity is demonstrated when measures of constructs that theoretically should not be highly related to each other are not found to correlate with each other. We excluded diseases such as asthma and influenza from the original SHC because these were regarded as diseases and not symptoms. The symptom instrument used may be considered to have good discriminant validity because it measured symptoms, which should be easy to distinguish from other variables.

*Convergent validity* is defined as "the extent to which the instrument tests the hypothesis or theory it is measuring" (163). This type of validity is dependent on a clear theoretical framework for the research topic. Symptom reporting is merely a descriptive term and is not based on distinct theoretical frameworks.

*Criterion validity* is a measure of whether the chosen instrument correlates well with the reference standard, which is usually a thoroughly validated instrument. Because there is no gold standard for assessing symptoms and symptom reporting, this type of validity is difficult to ascertain for the research in this thesis.

*Clinical utility* has been proposed as an additional measure to evaluate the quality of the instrument. The symptom list in the GP study may be perceived as time consuming and complex because of its length, which probably reduces its clinical utility. However, we did not intend to provide instruments for use in clinical practice or to develop a new symptom list to be validated for research or classification purposes. The composite symptom list was a compromise between the different factors important for research purposes. The importance of the total symptom load may provide useful clinical information, and this aspect is probably strengthened by the large number of symptoms included in the thesis studies.

## Self-rated health

SRH has established validity (*external validity*) and has been used to measure health for decades (164,165). The answers elicited by various instruments used to assess SRH are highly correlated (149), and good test–retest reliability of SRH has been demonstrated (*internal validity*) (166). SRH provides a useful summary of how patients perceive their own health (149) and is a widely used predictor of morbidity, mortality and disability (*predictive validity*) (142,167,168).

Because SRH seems to be a good indicator of objective health, it has been suggested that SRH could serve as a global measure of health status in a population (139). SRH has been shown to correlate strongly with health measures such as blood test results, body mass index, body weight and the presence of common chronic conditions such as hypertension, cerebrovascular disorder, diabetes mellitus and chronic bronchitis (139). However, qualitative studies have shown that not all individuals use the same frame of reference when evaluating their health and that the frame of reference may vary with age (169).

Some of the factors associated with poor SRH can be changed in a way that improves health, for example, improving the treatment of diseases, increasing physical activity or improving sleep (150). Further, SRH may reflect fluctuations in symptoms and health, based on continuous monitoring of health and body in an individual (164). SRH is thus susceptible to changes over time. The cross-sectional nature of these thesis studies did not allow for the examination of the possible changes in SRH related to changes in symptom burden, risk factors or disease.

It has been argued that the evaluation of symptoms from a standardized symptom questionnaire that asks only about the existence of symptoms may not be a valid indicator of whether the symptoms have a negative effect on health. Symptoms may reflect a person's interpretations of bodily sensations rather than an expression of illness (29). In reality, the instruments measure an individual's responses to sensations rather than the amount or extent of disease. However, the strong correlations with several of the outcome variables in this thesis suggest that the sum of major and minor symptoms constitute an important dimension for an individual's health.

In this thesis, the relationships between SRH and the number of symptoms was examined in both directions (from the number of symptoms to SRH in Paper I and from SRH to the number of symptoms in Paper III). There was a strong, linear relationship between the number of symptoms and SRH. Although the relationship between cause and effect on the number of symptoms and SRH cannot be deduced from these cross-sectional studies, these concepts are closely linked and may be bidirectional.

### 5.6. Bias

Bias can be defined as "any process at any stage of inference which tends to produce results or conclusions that differ from the truth" (170).

## The population study

Some studies have found that individuals with good health are more likely to respond to health surveys (*selection bias*). The low response rate of 54% in the population study may represent *non-respondent bias*; that is, responders may be healthier than non-responders (the "healthy volunteer effect") (171). The opposite may also be the case, where those who have experienced symptoms may be more interested in the study and therefore may respond more often.

In 2004, the inhabitants of Ullensaker municipality were younger than the Norwegian average. The response rate was higher among women than men and in middle-aged than in the youngest and oldest age groups. This selection bias may affect the generalizability of the study results because it may have resulted in an overestimation of the number of symptoms reported given that middle-aged women report more symptoms than other groups. On the other hand, a healthy volunteer effect may have led to an underestimation of symptom prevalence, which may have counterbalanced this finding.

The dropout rate of seniors in surveys is often large. The elderly population has been characterized as "the happiest live the longest", which may give an impression of better health and quality of life (*survival bias*) in the older age groups.

Self-reporting is a type of reporting behaviour that can lead to *response style bias* (170). Symptoms are based on personal experience and are therefore best assessed through self-reports, such as questionnaires or interviews. The threshold for reporting symptoms is individual in the sense that some people are likely to report clinically insignificant or transient discomfort, whereas others may consider similar symptoms to be unimportant and may not report them. However, there are no good alternatives to self-report in studies of symptoms.

We consider the limited time frames of recall of symptoms (7 and 30 days) to be a strength of the thesis studies because it should have increased the accuracy of recall (172). Comparable studies that recorded the number of symptoms experienced during the past year or lifetime symptoms are likely to have been affected by *recall bias* (173). It is expected that the number of symptoms experienced can accumulate over time. However, a large study of general practice in 14 countries found that 43% of the lifetime symptoms reported at the baseline were lost to follow-up 12 months later (173). A large Norwegian population study found a 76–80% overall loss of lifetime symptoms at follow-up 11 years later (172).

The imputation procedures (Paper I) increased the number of participants available for analyses, thus reducing the *missing data bias* (170). The sensitivity analyses indicated that the imputations were conservative in the sense that imputation would weaken rather than strengthen the associations found. However, imputation can introduce some degree of bias, which is a limitation that should be considered.

The SNQ operates with dichotomous categories to register musculoskeletal pain symptoms, whereas the SHC has categories of the levels of severity of the symptoms. The responses to SHC (Paper I) were dichotomized into the categories "not at all" and "at least a little" bothered by the symptoms listed because the intention was to capture minor symptoms. However, through the dichotomization of the variables, some information may have been lost because this procedure may have obscured differences between groups under comparison (*scale degradation bias*).

Preliminary analyses that included only symptoms reported to be experienced to "some" or "severe" degree were performed. Moving the cut-off of symptoms in the modified SHC to include only symptoms of high severity reduced the associations with symptoms from the SNQ. This suggests that the whole symptom iceberg, which includes even symptoms assessed as "a little bothered", may be important.

### The GP study

The participating GPs in the general practice study were recruited from meetings in counselling groups aimed at those wanting to become a specialist

in general practice. This approach may have recruited younger and more inexperienced GPs than the GP average (*selection bias*). The GP sample also included instructors at the meetings, who were already specialists and usually were experienced GPs.

A short presentation on symptom reporting for potential participating GPs was given before the study began. Although the specific research questions and hypotheses were not addressed, the introduction may have primed the GPs about the intention of the study. This approach may have facilitated the recruitment of GPs with a particular interest in symptom research, who may have had greater knowledge about and have been more positive about the topic. Theoretically, this may have also attracted more patients with many symptoms to consult a GP with a reputation for engaging in the disorders in question (*centripetal bias*) (170). However, GPs do not select patients on their list and those in the study were asked to include consecutive patients on a random day in practice, regardless of the reason for encounter. Therefore, we think the potential for *selection bias* of patients is modest.

# 6. DISCUSSION OF THE MAIN RESULTS

In research on health-promoting measures, prevention of health problems, diagnosis, treatment and rehabilitation, it is important to include the patient's perspective. This perspective was chosen in our research along with a focus on self-reported symptoms and self-assessed health, which were also linked to the GPs' diagnoses.

The following discussion refers to the large variation in the instruments used to map symptoms and SRH. This variability poses a challenge, especially in relation to prevalence. As much of this thesis research has revolved around studying associations, the methodological challenges pose a minor problem.

This section first discusses symptom reporting in the population and in general practice patients, and then proceeds to discuss symptoms and symptom patterns and diagnoses. This is followed by discussion of SRH in general practice patients and in the population. Finally, the discussion ends by considering the associations between symptoms and SRH with a number of socio-demographic variables.

## 6.1. Symptom reporting in the population and in general practice

### 6.1.1. Symptoms

Most of the population (92%) reported at least one symptom during the previous 30 days (Paper I). It is a common finding that a large part of a population reports symptoms (48,174). A Norwegian population study found that 96% of the population reported at least one symptom the past 30 days

(45). In a Danish study, 90% of the population reported at least one symptom in the preceding 4 weeks (11).

The mean number of symptoms in the population study in this thesis was 6.0 of a maximum of 23 symptoms. In a large Danish population study the mean was 5.6 of 44 possible symptoms (11), whereas in a UK population study the mean was 3.7 of 25 possible symptoms (103). The seemingly higher symptom prevalence in the Norwegian population is consistent with the higher number of musculoskeletal symptoms reported by Norwegians compared with the populations in other European countries (175).

In the general practice study, the patients reported a mean of 7.5 of the 38 listed symptoms during the previous week. Patients in primary care are known to report more symptoms (2) than unselected populations (10). A study of medical outpatients found that patients declaring to be asymptomatic when making an appointment for a routine health check-up spontaneously reported a mean of 4.2 symptoms (106).

There are some methodological differences between the two studies reported in Papers I and II, including the different number of symptoms included and different time frames, which make direct comparisons problematic. However, a mean of 6.0 of 23 symptoms in the population versus 7.5 of 38 in GP patients seems to be fairly similar.

The middle-aged (40–60 years) participants reported the most symptoms, both in the population and among GP patients. The number of symptoms were similar in the groups younger than 40 years and older than 60 years. The number of symptoms is expected to increase with age because health status usually declines with increasing age. However, it is a common finding that the number of symptoms increases with age, peaks between 50 and 60 years, and then decreases in older age groups (176,177), and the results of this thesis are consistent with these other findings. A lower number of symptoms at older

age may indicate that some of the symptoms reported by younger people may be those that older people tend to ignore and thus not report.

There are significant differences in prevalence between individual symptoms. For example, the prevalence of many symptoms, such as neck pain (178), LBP (179) and symptoms related to stress (180) decreases with increasing age. The symptom patterns according to age found in this thesis research differ from those reported in some earlier studies (181). One UK study found that people aged 18–24 years reported more symptoms than those aged 50– 60 years (10).

Women had higher mean number of symptoms than men, in both the population study (6.7 vs. 5.1) and the general practice study (8.1 vs. 6.5). It is a common finding that women report more symptoms than men (2,10,48,180,181). Interestingly, however, a large UK-based population study found that the sex differences remained significant for only four of 25 symptoms after controlling for socio-demographic factors (10). Another population study found no differences between men and women for two-thirds of the symptoms that prompted the patient to contact a GP (11). This finding suggests that women do not see a doctor with a given symptom more often than men.

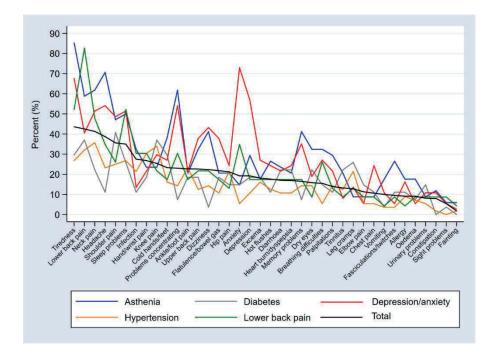
#### 6.1.2. Individual symptoms

We found that tiredness, LBP, neck pain, headache, shoulder pain and sleep problems were the most prevalent symptoms among the general practice patients. These are the most frequently reported symptoms in both population studies (10,45,180) and other studies from general practice (2,107,182). These findings suggest that the symptom panorama is similar between the population and patients in general practice. Because not all symptoms are evenly related to the health outcomes, some symptoms are likely to predict a worse outcome than others. In the GP study, seven of the 38 symptoms were significantly associated with poor SRH: tiredness, hip pain, depression, problems concentrating, anxiety, headache and LBP.

Our research group has previously demonstrated that the association between symptoms and function differ according to the specific symptoms (28). In that study, sleep problems, depression, anxiety and LBP were associated with reduced function. In a recent Norwegian population study, pain, fatigue and sleep problems were the symptoms most strongly associated with a high symptom burden (181).

### 6.1.3. Symptoms, symptom patterns and diagnoses

In this thesis research, a higher number of symptoms was reported by patients with asthenia and depression/anxiety diagnoses; that is, 44% and 23% more symptoms, respectively, were reported by patients with these diagnoses than by patients with all other diagnoses. However, despite the significant (and clinically relevant) differences between the symptoms, the pattern of symptoms was distributed similarly across the selected diagnoses (Figure 7). For most of the symptoms, the risk that the symptoms were reported by patients with a given diagnosis was not higher than that for those without the diagnosis. These findings indicate that patients in general practice share a common pattern of symptoms that appears to be partly independent of the diagnosis given.



*Figure 7.* Prevalence of individual symptoms according to the selected diagnoses compared with the total prevalence of symptoms in the study population.

This finding suggests that only some of the symptoms are relevant to the diagnosis. However, given the limited results, it is unclear where a line can be drawn between "relevant" and "irrelevant" symptoms.

On the other hand, the similarities in symptom pattern suggests that symptoms are not necessarily an indication of disease. Many of the reported symptoms may represent a natural part of being a human.

Kroenke reported that many of the same symptoms recur in patients with multiple symptoms (37). Statistical clustering of symptoms has been analysed over many years of studying this issue, and the results depend partly on the symptoms included and the study setting (78). In 1984, Crook et al. found that clustering of symptoms occurred in some physical illnesses and that pain at different sites had similar characteristics (183). A Norwegian survey of subjective health complaints, assessed with the SHC inventory in 2002, found that, during the preceding month, 80% of the population reported

musculoskeletal, 65% pseudoneurological (tiredness, depression, dizziness), 60% gastrointestinal and 54% influenza-like (45) complaints. Overall, the symptoms tend to concentrate around 4–5 major symptom clusters: musculoskeletal pain, and gastroenterological, cardiopulmonary, neurological and infectious complaints (184).

However, a Danish study found strong correlations between symptoms across the different clusters (185). Furthermore, when low and moderate correlations between symptoms were included, all symptoms except two of the 19 studied correlated with the other symptoms. This finding adds to the complexity of interpreting symptoms.

### 6.2. Self-rated health in the population and in general practice

"Is there any pleasure that can be compared to this sudden transition from the most unbearable pain as the stone comes out, to the feeling of a magic trick, to find the radiant light of a health so free and complete, as it happens under the most sudden and violent seizures of a renal colic. Does not the endured pain more than offset the joy of the rapid improvement? How infinitely more beautiful does health seem to me with the disease attack so close and near."

Michel de Montaigne, French philosopher (1533–92)

In the population study, 24% reported very good, 41% good, 24% average, 9% poor and 2% very poor SRH. The corresponding numbers from the GP patients were 16% very good, 36% good, 25% average, 20% poor and 2% very poor SRH.

After very good and good SRH were dichotomized into good SRH, and average, poor and very poor SRH into poor SRH, 35% of the population and 48% of the GP patients reported poor SRH. Not surprisingly, the population reported better health than the patients in general practice, and more people in the population reported very good SRH and fewer reported poor SRH.

Swedish and Norwegian population studies that used a five-response instrument to assess SRH found poor SRH was reported by 31% (very poor + poor + neither good nor poor) (136) and 38% (very bad + bad + fair) (186), respectively. In a Norwegian general practice study in 2018, 35% of the patients reported excellent or very good, 39% reported good and 26% reported fair or poor SRH (150). The differences in prevalence rates in poor SRH reflected mainly methodological differences. SRH declines with increasing age (150,151). According to Statistics Norway, in 2019, poor or very poor SRH was reported by 3% of the population aged 24 years or younger, 5% of those aged 25–44 years, 9% of those aged 45–66 years and 10% of those aged 67 years or more (126). In this thesis research, the highest prevalence of poor SRH was in patients aged 40–59 years, which was also found for the number of symptoms. A slightly lower symptom count in the older age groups may partly explain this result (152).

Others have reported that poor SRH reaches a maximum in middle-aged people (187). A plausible explanation for a seemingly better SRH in older people is that older people have an age-adjusted expectation of health (133). In this context, adaptation to a chronic disease would reduce the perception of the consequences of the disease. Older people are probably also better equipped for adapting to worsening health, either by decreasing their aspirations (188) and lowering their expectations or by comparing themselves with people who are worse off (189). When general health fails, people may appreciate other things in life than what they did at a younger age (190). Perhaps, then, SRH becomes less based on functional status.

Inherent generational differences may also influence SRH (151). Attitudes and values that configure health behaviours and health perceptions are likely to change over time, and people born within the same time period may share behaviour shaped by circumstances specific to their generation. It is also possible that a generation used to having little early in life but more later in life may be more satisfied with their own health (191).

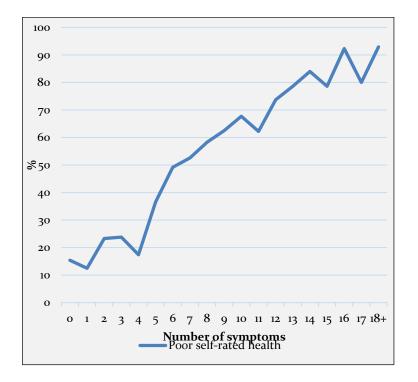
In the GP study (Paper III), the prevalence of poor SRH did not differ between men and women, a result that is consistent with findings of a recent Norwegian GP study (150). A study comparing populations between Florence in Italy and Tampere in Finland also found no sex differences in SRH in either of the countries, although both women and men in Florence were 3–4 times more likely to report good SRH than those in Tampere (192). By contrast, a large French population study found that women reported poorer SRH than men (193). Despite the mixed results for sex differences, SRH seems to be a valuable measure in both men and women. A study that examined SRH in 19 European countries found that SRH was a good proxy for mental and physical health status in both men and women in all countries (194).

## 6.3. Number of symptoms, SRH and associated factors

Når de store bekymringer trenger sig på, blir de daglige ærgrelser latterlig små. Men når atter de store blir vejrende hen, så vokser de mindre sig store igen. Det er som man bærer sin sorg i en bylt som er så-og-så stor og som skal være fyldt. Og skal sådan en bylt være rimelig let, må man gøre den lille og knytte den tæt. – Piet Hein, Danish mathematician and poet (1905–1996)

#### 6.3.1. Number of symptoms and SRH

In this thesis research, poor SRH increased almost linearly with an increasing number of symptoms (Figure 8). A high number of symptoms was most strongly associated with poor SRH in both general practice patients and the population, as reported in another study (195).



*Figure 8.* Percentage of GP patients reporting poor SRH according to the number of symptoms in the past week.

Other studies have demonstrated that a high number of symptoms is associated with poor SRH (32,196) and reduced function (134). A large study analysed data from nine population studies to determine the value of the total symptom score as a predictor of health status (197). The authors found a strong association between health status and total symptom score, which reflected both the number and severity of the symptoms. A review of 47 studies that included both population and general practice settings also found a clear correlation between an increasing number of symptoms and declining functional status (198).

We have previously found that the association between the number of symptoms and health is independent of the type or severity of the symptoms studied (28,199). The strong association between total symptom load and SRH is a consistent finding regardless of whether the symptoms are medically explained or unexplained (57,152). In addition, the strong association between SRH and the number of symptoms remains even after adjustment for the effects of medical comorbidity (198) both in the population (177) and among general practice patients (200).

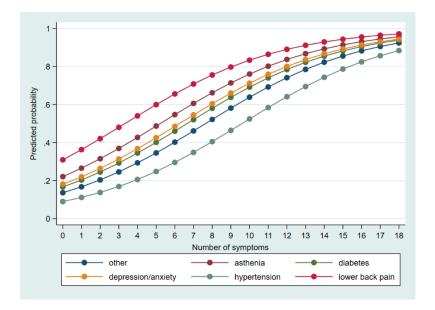
A high total symptom load may predict poor SRH regardless of the nature of the symptoms (88). Rosendal et al. reported that certain symptom patterns contain important prognostic information (92). They suggested that the prognosis for health outcome is likely to be worse in people with more symptoms and organ systems involved and with a higher frequency of symptom recurrence.

### 6.3.2. Prevalent diagnoses

The high number of different diagnoses reported by the GPs (n = 321) reflects the large diversity of health problems these GPs encounter (201). However,

the low number of patients for each diagnosis does not allow one to draw firm conclusions about the associations between individual symptoms and diagnoses (202).

In the GP study, patients who were given a diagnosis of asthenia, LBP or depression/anxiety reported more symptoms and poorer SRH than those with all other diagnoses. However, the predicted probability of reporting poor SRH increased with an increasing number of symptoms for all of the selected diagnoses (Figure 9).



*Figure 9.* The predicted probability of poor SRH according to the number of symptoms reported by the patients and the most prevalent diagnoses given by their GPs.

Receiving a disease diagnosis will normally cause a worsening of SRH with a spike in poor SRH occurring typically in the year of the diagnosis (203). A large Norwegian population study (HUNT 2) found that people with undiagnosed diabetes mellitus, hypertension or hypothyroidism reported poorer SRH when made aware of their diagnosis (204). This suggests that cognition and knowledge of a disease are strongly related to SRH (203).

A decline in SRH may start many years before a diagnosis is made, which suggests that SRH might capture pathological changes before and beyond a diagnosis (156). It is possible that SRH instruments can capture illnesses that are in a latent or prodromal stage when they may present only as subtle symptoms (205).

A follow-up study found that people who died at the age of >65 years had poorer SRH by 11–12 years before death compared with the surviving controls (206). SRH may also predict certain disease outcomes, such as mortality from cancer or cardiovascular disease, better than physician-rated health (144).

## 6.3.3. Chronic conditions

The studies in this thesis found an increasing prevalence of poor SRH and a higher number of symptoms with an increasing number of chronic conditions. Poor SRH is frequently associated with having chronic conditions (207). In addition, people with chronic diseases are likely to report a higher number of symptoms (177,181).

In a primary care study, Kroenke et al. found a weak association between the number of chronic conditions and health outcome (34). In that study, the number of physical disorders accounted for only 4.5% of the variance, whereas symptom severity explained 35.2% of the variance in patients' self-rated general health. The results of a large US population study showed that functional limitations are more important for SRH than the number of chronic conditions (208). This suggests that the consequences of symptoms or disease rather than the disease itself affect how individuals rate their health (209).

The finding of a weaker association between SRH and health outcome when a disease is asymptomatic compared with symptomatic (210) means that a health problem may be seen as minor if it does not affect daily life, but more severe if it limits daily life considerably. A follow-up study that looked at the associations between SRH and severity scores for chronic conditions found that people who perceived their own health to be better than their objective health measures showed 5 years later, also had better function and less pain (211).

### 6.3.4. Social security benefits

Socio-economic factors are associated with SRH (212). The founder of the concept of illness perception, sociologist David Mechanic, argued that a socio-economic gradient is associated with all levels of morbidity and mortality, and stated that "socio-economic status is of major importance in determining exposure to disease risk and in shaping health and illness behaviour responses" (213).

In the two studies in this thesis, those who reported the most symptoms and the worst SRH also received social security benefits. This association is known from previous studies (10,88). Reporting a high number of symptoms per se is associated with increased sick-leave (214). A cross-sectional study conducted in 14 European countries found that employment status was most strongly associated with poor SRH (151). In a Finnish follow-up study of employees aged 40–60 years, SRH was a strong predictor of disability retirement 8–10 years later (145).

Differences in welfare systems and public health services between countries may influence SRH. In a study of people aged 25 years or above from 21 different European countries, those from countries with Scandinavian and Western European welfare systems reported better SRH than people from Eastern and Southern Europe (215).

In this thesis research, people with a lower educational level reported both poorer SRH (Paper III) and a higher number of symptoms (Paper I). Education is regarded as one of the most important socio-economic predictors of health status (213). Lower educational level is associated with a higher number of symptoms (10,181), which implies poorer health. Education influences how individuals perceive their own health (216) and their ability to obtain and apply health knowledge toward health-promoting behaviour (159).

Lifestyle habits such as obesity and lack of physical activity are known to contribute to a high number of symptoms and a poor SRH (141). The findings from Paper I are consistent with this association.

### 6.3.5. Perspectives on SRH

There is not always agreement between the patient's and doctor's assessment of the patient's health (144). In a study of male patients aged 64–84 years, 50% of the patients rated their health as good, but only 32% of their physicians rated the same patients' health as good. When a shared understanding might be difficult to achieve, the GP may contribute to patient empowerment by exploring, recognizing and respecting the patient's symptoms, SRH and disease attribution (5).

Many people with serious and persistent disabilities report that they experience a good or excellent quality of life even when external observers might consider that these individuals live an undesirable daily life. This phenomenon is described as "the disability paradox" by Albrecht (217) and is explained as "experiencing a good quality of life, despite adverse conditions", which also implies that "a poor quality of life reflects the absence of such a balance" (217). This paradox can be understood in the context of how some patients with chronic disorders learn to cope and change their expectations and, through this, may perceive their health as improved, even though others would see their illness as unaltered (169).

Bonsaksen et al. state that health is not opposite to disease but may instead be seen as "a product of the ongoing interaction between the person, the environment and relevant disease conditions" (218). From this perspective, illness and health problems do not necessarily mean poor SRH (204). Instead, SRH may be seen as an individual's ability to manage the various health challenges and demands of everyday life, including the ability to cope with stress (117).

Paterson asserts that living with illness is living with wellness at the same time (219). Whether illness or wellness is at the foreground of attention depends on a number of factors, including the time since the diagnosis and the symptom burden (41).

In a qualitative study in general practice, personal and social resources are mentioned as essential means for tolerating and managing the burden of disease (5). When adversity is encountered, optimistic people might be more likely to reassert effort (220). To the extent that the obstacles that an individual faces are surmountable, optimism may therefore result in better health outcomes.

SRH may represent complex patterns of adaptation to body, mind, social and environmental challenges (221), adaptations that may also be influenced by age or culture (168). SRH can therefore be seen as a multidimensional phenomenon that provides information about both physical and mental wellness, and is influenced by contextual circumstances (151).

# 7. CONCLUSIONS

The Norwegian Society of General Practitioners has agreed to focus on seven selected specified issues with respect to primary care, known as the "theses for general practice". According to these theses, "the general practitioner should give the patient faith in their own mastery of everyday life and health" and GPs are encouraged to "use words that promote health" in their communication with their patients (222).

We have followed up this recommendation and studied self-reported symptoms and SRH, and linked these to diagnoses given by the GP. The findings may be summarized as follows.

Experiencing symptoms is the rule rather than the exception among patients in general practice and in the population.

Patients in general practice report a variety of symptoms that are partly independent of the diagnosis given by their GP and they share a common pattern of symptoms across various diagnoses. This implies that the experience of symptoms is not necessarily linked to disease but might be a natural part of being a human.

Patients with asthenia and depression/anxiety report a higher number of symptoms and poorer SRH than those with other diagnoses.

A high number of symptoms is strongly associated with poor SRH, in both the population and general practice patients. There is no clear distinction between what represents good and poor SRH.

Of the individual symptoms, tiredness, hip pain, depression, problems concentrating, anxiety, headache and LBP are associated with poor SRH.

GPs may be better able to understand their patients' needs by obtaining information about all symptoms experienced by a patient from time to time and asking the patients explicitly about all symptoms, not just those presented during a consultation.

The finding that the likelihood of reporting poor SRH seems to be directly related to the number of symptoms reported should prompt GPs to have a greater awareness of patients presenting with many symptoms.

# 8. IMPLICATIONS

"Medicine is a science of uncertainty and an art of probability."

– Sir William Osler, Canadian physician (1849–1919)

### 8.1.1. Research implications

We have approached the relationship between self-reporting of symptoms and medical diagnosis. With the small material and the large variety of diagnoses set by the general practitioners, only a few diagnoses could be examined. There is a need for more research on the associations between individual symptoms, symptom patterns, number of symptoms and diagnoses.

Not all symptoms a patient reports are relevant to making a diagnosis. Knowledge of all the symptoms a person experiences might be seen as noise in the diagnostic process. On the other hand, information about the whole spectrum of symptoms may provide additional useful information.

A patient's SRH and functional capacity deteriorates with an increasing number of symptoms, while the likelihood of having a medically unexplained condition increases. Symptom research should therefore cover a broad spectrum of symptoms.

The relationship between symptoms and health outcomes reflects the number, type and pattern of symptoms (185), and it is important to focus on all three aspects in future work.

The similarities in symptom patterns across prevalent diagnoses calls for future unified approaches to symptom research across medical specialties to prevent premature causal assumptions. One of the biggest challenges for symptom research is the group of patients reporting many symptoms and whose symptom patterns do not fit clearly established diagnostic criteria. Many of these patients are seriously affected and the results of recommended interventions have so far been disappointing. Two different approaches to multi-symptom conditions have been taken in research on this topic. The first is "splitting" to allow the definition of a large number of clinical syndromes, each with their own specific criteria and theories on their aetiology. The alternative approach is "lumping", in which the great overlap of symptoms prompts a look for similarities and common explanations for the conditions. From a research perspective, a long-term follow-up study of patients reporting a high number of symptoms may provide an alternative, more neutral approach.

The thesis results indicate that not all symptoms are associated with disease. For practical and research purposes, there are reasons to question many of the existing definitions of a symptom as a sign of disease. The existing heterogeneity in symptom instruments and SRH instruments, which admittedly this work also contributes to, indicates the need to develop instruments for international use. This will enable direct comparisons across studies and between different countries.

Research on symptoms as a phenomenon may allow for future evidencebased education and improved treatment of symptom patients seen in primary care (2).

## 8.1.2. Clinical implications

Better insight into symptom reporting in the population and among patients in general practice may contribute to greater understanding of symptoms both as markers of disease and as the normal human experience.

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Public knowledge of common symptom prevalence may reduce health concerns and provide reassurance for healthy people experiencing symptoms (101). Such knowledge might also reduce unnecessary health-care seeking, limit excessive medical examinations and reduce the possibility of overdiagnosis.

We recommend that, in some consultations, GPs ask patients explicitly about concurrently present but not presented symptoms and how patients assess their own health. Such an approach may provide information about an individual's health, which may be different from the view of health professionals and may help the GPs to better understand their patients' needs.

Physicians who can identify factors associated with SRH and are interested in their patients' expectations for health (127) have the potential to promote health-improving activities and prevent patients from entering a sick-role (5).

Reassurance from the GP (223) and a caring rather than a curing approach to the patient when "nothing seems to be wrong" may increase the likelihood of improving (224) and maintaining (225) a good SRH. Consequently, "the ability to overcome difficulties experienced in different areas of one's life with perseverance" (resilience) may improve (226).

A salutogenic approach, that is, asking patients about what keeps them healthy and then implementing these "health resources" during consultations is encouraged (227).

Conditions with multiple symptoms may represent diagnostic uncertainty. Downplaying this uncertainty by the GP may lead to iatrogenic strengthening of the patient's complaints (224) and more illness worry (228). By providing good communication about medical uncertainty, the GP may help to reduce the patient's health anxiety, improve coping strategies (229) and facilitate better health outcomes (230) in patients with a high symptom load. The ability of GPs and patients to work together to reframe the presence of "symptoms only" to be seen as a surmountable challenge rather than a threat, may have a beneficial impact on patients' SRH.

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### 10. APPENDICES

Appendix A: Ullensaker questionnaire 2004

Appendix B: General practice study – patient questionnaire

Appendix C: General practice study – GP questionnaire

### APPENDIX A



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UNIVERSITETET I OSLO

Institutt for allmenn- og samfunnsmedisin Postboks 1130 Blindern 0318 Oslo

### Muskel- og skjelettplager i Ullensaker 1990-2004

Muskel- og skjelettplager er noe de fleste har fra tid til annen. Plager fra ledd og muskler er hyppig årsak til sykmelding og uførhet. Kunnskapen om slike plagers forløp er mangelfull og vi vil derfor be deg om å delta i en spørreundersøkelse.

Vi gjorde lignende undersøkelser i Ullensaker i 1990 og 1994. Hensikten med den nye undersøkelsen er å følge slike plager over lang tid. Spørreskjemaet du har mottatt, blir sendt til omtrent 1/3 av Ullensakers befolkning. Utvalget er basert på fødselsår og adressene er hentet fra Folkeregisteret. I tillegg sendes skjemaet til personer som bodde i Ullensaker i 1990 og/eller 1994, og som deltok den gangen, og siden har flyttet ut av kommunen.

For de som besvarte undersøkelsen i 1990 og/eller 1994 ønsker vi å kunne sammenholde resultatene. Det gjør vi ved hjelp av et registreringsnummer. Nummeret gir oss også muligheten til å sende en påminnelse til dem som ikke har svart.

All databehandling vil foregå konfidensielt. Resultatene av undersøkelsen vil bli offentliggjort, uten at den enkelte kan gjenkjennes. Det kan bli aktuelt å gjennomføre en oppfølgingsundersøkelse i 2010. I så fall vil du motta ny informasjon og ny forespørsel. Etter at prosjektet er avsluttet vil opplysningene bli anonymisert, senest i 2013. Prosjektet er tilrådd av Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste A/S og Regional komité for medisinsk forskningsetikk.

Deltagelse i undersøkelsen er frivillig. Du kan unnlate å svare på enkeltspørsmål selv om du deltar. Du kan trekke deg fra videre deltakelse i prosjektet når som helst uten at du behøver å oppgi noen grunn. Forskningsprosjektet utføres av Ullensakerundersøkelsene, et prosjekt ved Universitetet i Oslo, Institutt for allmenn- og samfunnsmedisin, med lege og forsker Bård Natvig som prosjektleder. Praktisk gjennomføring av undersøkelsen gjøres i samarbeid med TNS Gallup.

Har du spørsmål om undersøkelsen eller trenger hjelp til utfylling av skjemaet kan du ringe gratis til TNS Gallup på grønt nummer, tlf **800 84 700** eller sende e-post til prosjektleder: <u>bard.natvig@medisin.uio.no</u>.

Vi ber deg fylle ut spørreskjemaet og returnere det i vedlagte svarkonvolutt. Det vil være til stor hjelp for oss om du er nøyaktig når du setter kryss, og at du bruker **blå penn**. De fleste spørsmålene besvares ved å sette et kryss i det svaralternativet som passer best , slik det er vist her:

Slik: 🛛

Ikke slik

Tall skal skrives slik:

1234567890

Blant dem som sender inn spørreskjemaet trekker vi ut 50 deltagere som får 3 Flax-lodd hver. Vinnerne tilskrives etter trekning 2.mars 2005.

Med hilsen [signature removed]

[signature removed]

Dag Bruusgaard Lege, professor, dr.med. Bård Natvig Lege, forsker, dr.med.



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Personopplysninger		
<b>1. Kjønn</b> Mann□ Kvinne□	2. Fødselsår	6. Ditt fødeland (mors bosted da du ble født) Skriv med blokkbokstaver
<b>3. Sivilstatus</b> Gift/samboende Separert/skilt Enke/enkemann Enslig		7. Fars fødeland Skriv med blokkbokstaver
4. Høyde cm	5. Vekt	8. Mors fødeland Skriv med blokkbokstaver

### Aktivitet, utdanning og arbeid

9. Utdanning, sett kryss ved den høyeste utdannelsen du har
Grunnskoleutdanning
Yrkesskole
Videregående utdanning
Høyskole eller universitet (1-4 år)
Høyskole eller universitet (> 4 år)

### 10. Egen yrkesstatus

Yrkesaktiv utenfor hjemmet
Hjemmeværende
Arbeidsledig
Under attføring pga sykdom
Uføretrygdet
Pensjonert
Under utdanning

Hvis du ikke har inntektsgivende arbeid gå til spørsmål 16.

11. Hvor mange timer jobber du med inntektsgivende arbeid i gjennomsnitt pr. uke?



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ti	mer

12. Har du vært sykmeldt siste året?	
Nei	]
Ja, mindre enn 1 uke	]
Ja, mellom 1 uke og 8 uker	]
Ja, mer enn 8 uker	]

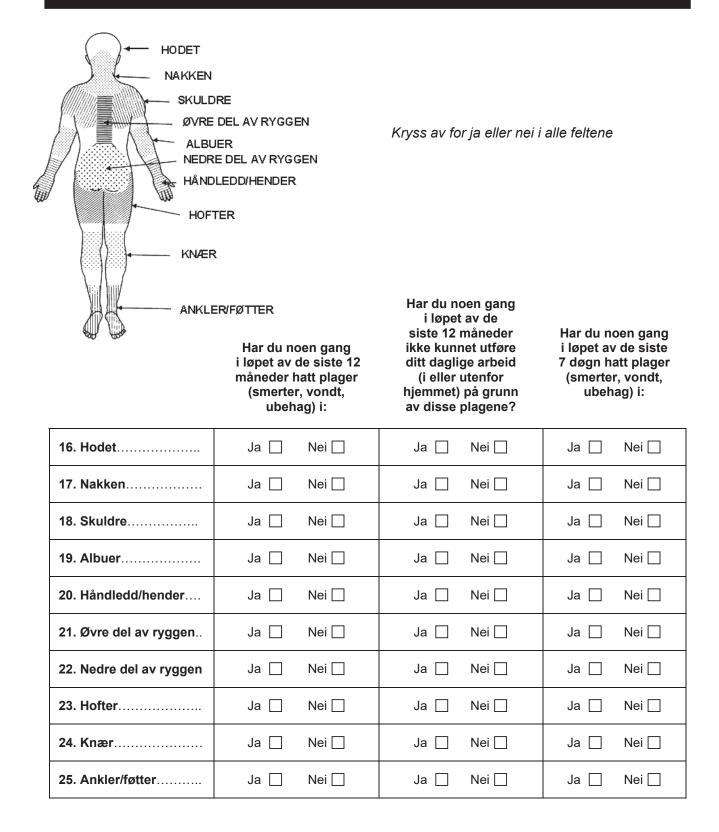
13. I hvilken grad er din evne til å utføre ditt vanlige arbeid nedsatt akkurat i dag?         Ubetydelig/ikke nedsatt         Uke særlig nedsatt         Moderat nedsatt         Mye nedsatt         Svært mye nedsatt
<b>14. Inneholder arbeidet ditt mye</b> <i>Flere svar mulige</i> arbeid med hendene over         skulderhøyde         belastninger i samme stilling over         lengre tid         gjentatte, ensidige bevegelser.         tunge løft.         mye sitting         mye ståing         høyt arbeidstempo.
15. Føler du at du har innflytelse på din egen arbeidssituasjon?         Meget lite



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### Muskel- og skjelettplager





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29. Har du fått stilt diagnosen slitasjegikt

(artrose) i kne, hofte eller hender av lege

og/eller på røntgen?

Middels	
	Ja, kne
Ikke så ille	Ja, hofte
Ikke hatt plager	Ja, hender
	Nei
27. Hvor mange år har du hatt muskel- og skjelettplager?         Har ikke hatt plager         Mindre enn 1 år         1-5 år         6-10 år         Mer enn 10 år         28. Hvor lenge har du sammenhengende hatt muskel- og skjelettplager siste 12 måneder?         Har ikke hatt plager         Mindre enn 1 uke         Daglig hele året	Nei   30. Har du fått stilt en av diagnosene leddgikt (revmatoid artritt) eller   Bekhterevs sykdom av lege?   Ja, leddgikt   Ja, Bekhterevs sykdom   Nei   31. Omtrent hvor mange ganger har du i   løpet av det siste året vært hos   Lege   Fysioterapeut   Kiropraktor   Alternativ behandler
	Alternativ behandler
Levevaner	
32. Hvordan sover du vanligvis?	35. Hvor mye bruker du kroppen din i fritiden
	(slik at du blir svott eller andnusten)?
Dårlig	(slik at du blir svett eller andpusten)?
Middels	Ingenting
	Ingenting Mindre enn 2 timer per uke
Middels	Ingenting Mindre enn 2 timer per uke Mellom 2 og 4 timer per uke
Middels	Ingenting Mindre enn 2 timer per uke
Middels	Ingenting Mindre enn 2 timer per uke Mellom 2 og 4 timer per uke
Middels Godt	Ingenting Mindre enn 2 timer per uke Mellom 2 og 4 timer per uke
Middels Godt	Ingenting
Middels	Ingenting
Middels Godt	Ingenting
Middels	Ingenting

4



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26. Hvor ille har dine plager vært?

Svært ille

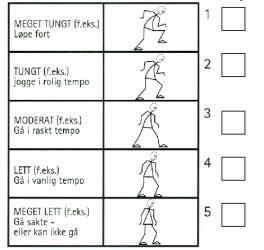
Ille.....

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### Funksjonsevne. For hvert spørsmål sett et kryss i boksen ved siden av det alternativet som passer

### 37. Fysisk form

De siste 14 dager...Hva var den tyngste fysiske belastningen du greide/kunne greid i minst to minutter? Sett kryss her



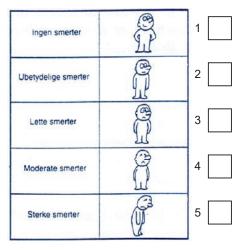
#### 39. Daglige aktiviteter

De siste 14 dager... Har du hatt vansker med å utføre vanlige gjøremål eller oppgaver enten innendørs eller utendørs, pga din fysiske eller psykiske helse?



### 41. Smerter

De siste 14 dager... Hvor sterke smerter har du vanligvis hatt?





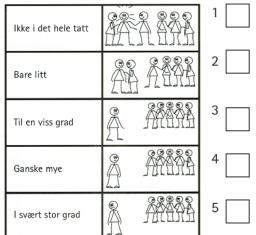
### 38. Følelsesmessige problemer

De siste 14 dager... Hvor mye har du vært plaget av psykiske problemer som indre uro, angst, nedforhet eller irritabilitet?



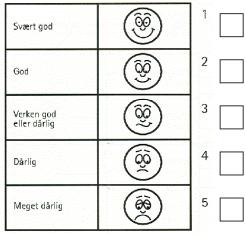
#### 40. Sosiale aktiviteter

De siste 14 dager... Har din fysiske eller psykiske helse begrenset dine sosiale aktiviteter og kontakt med familie, venner, naboer eller andre?



### 42. Samlet helsetilstand

De siste 14 dager... Hvorledes vil du vurdere din egen helse fysisk og psykisk i alminnelighet?



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43. Har du av helsemessige grunner hatt vansker med å utføre følgende aktiviteter i løpet av den
siste uken?

siste uken?					
Sett ett kryss for hver aktivitet	Ingen vansker	Lite vansker	Middels vansker	Mye vansker	Kan ikke
Stå					
Gå mindre enn 1 kilometer på flat mark					
Gå mer enn 1 kilometer på flat mark					
Gå på skiftende underlag					
Gå i trapper					
Handle dagligvarer					
Ta på sko og strømper					
Plukke opp en mynt fra et bord med fingrene					
Holde styr på et ratt med hendene					
Kjøre bil					
Lage mat					
Skrive					
Utføre vanlige oppgaver alene					
Drive med dine fritidsaktiviteter					
Kle av og på deg					
Løfte en tom bruskasse fra gulvet					
Bære en handlepose i hendene					
Bære en liten sekk på skuldrene eller ryggen					
Skyve og dra med armene					
Gjøre vanlig rengjøring					
Gjøre klesvask					
Sitte på en kjøkkenstol					
Bruke bil som passasjer					
Bruke kollektivtransport som passasjer					
Være oppmerksom og konsentrert					
Arbeide i gruppe					
Rettlede andre i deres aktiviteter					
Mestre ansvar i dagliglivet					
Mestre dagliglivets påkjenninger og belastninger					
Takle kritikk					
Styre sinne og aggresjon					
Huske					
Oppfatte muntlige beskjeder					
Oppfatte skriftlige beskjeder					
Snakke					
Delta i samtale med flere personer					
Bruke telefon					
Se på fjernsyn					
Lytte til radio					



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### Psykisk helse

# **44. Hvordan har du hatt det de 2 siste ukene?** *Sett ett kryss for hver linje*

Mye mindre	Mindre enn	Samme som	Bedre enn D
enn vanlig □	□ vanlig	vanlig	
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt	enn vanlig □	enn vanlig	enn vanlig □
Mye mindre	Mindre enn	Samme som	Mer enn 🛛 🖂
enn vanlig □	vanlig □	vanlig	
Mye mindre	Mindre enn	Samme som	Mer enn 🛛 🖂
enn vanlig □	vanlig □	vanlig	
Mye mindre	Mindre enn	Samme som	Bedre enn
enn vanlig □	vanlig □	vanlig	vanlig
Mye mindre	Mindre enn	Samme som	Bedre enn
enn vanlig □	vanlig □	vanlig	vanlig
Mye mindre	Mindre enn	Samme som	Mer enn
enn vanlig □	vanlig □	vanlig	vanlig
Mye mindre	Mindre enn	Samme som	Mer enn 🛛 🖓
enn vanlig □	vanlig □	vanlig	
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt	enn vanlig □	enn vanlig	enn vanlig □
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt	enn vanlig □	enn vanlig	enn vanlig □
Mye mindre	Mindre enn	Samme som	Mer enn 🛛 🖓
enn vanlig □	vanlig □	vanlig	
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt	enn vanlig □	enn vanlig	enn vanlig □
Mye mindre	Mindre enn	Samme som	Mer enn 🛛 🖂
enn vanlig □	vanlig □	vanlig	
lkke i det	lkke mer	Heller mer	Mye mer
hele tatt □	enn vanlig □	enn vanlig	enn vanlig □
lkke i det	lkke mer	Heller mer	Mye mer
hele tatt □	enn vanlig □	enn vanlig	enn vanlig □
lkke i det	lkke mer	Heller mer	Mye mer
hele tatt □	enn vanlig □	enn vanlig	enn vanlig □
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt □	enn vanlig □	enn vanlig	enn vanlig □
Mye mindre	Mindre enn	Samme som	Mer enn
enn vanlig □	vanlig □	vanlig	vanlig □
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt □	enn vanlig □	enn vanlig	enn vanlig □
Ikke i det	lkke mer	Heller mer	Mye mer
hele tatt	enn vanlig □	enn vanlig	enn vanlig □
	enn vanlig   Ikke i det hele tatt   Mye mindre enn vanlig   Ikke i det hele tatt   Ikke i det hele tatt   Mye mindre enn vanlig   Ikke i det hele tatt   Ikke i det hele tatt	enn vanligVanligIkke i det hele tattIkke mer enn vanligMye mindre enn vanligMindre enn vanligMye mindre enn vanligIkke mer enn vanligIkke i det hele tattIkke mer enn vanligMye mindre enn vanligMindre enn enn vanligIkke i det hele tattIkke mer enn vanligMye mindre enn vanligMindre enn vanligIkke i det hele tattIkke mer enn vanligIkke i det hele tattIkke mer enn vanlig <t< td=""><td>enn vanlig       vanlig       vanlig       vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig       Ikke mer enn vanlig         Mye mindre enn vanlig       Mindre enn vanlig       Samme som vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Mye mindre enn vanlig       Mindre enn vanlig       Samme som vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i</td></t<>	enn vanlig       vanlig       vanlig       vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig       Ikke mer enn vanlig         Mye mindre enn vanlig       Mindre enn vanlig       Samme som vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Mye mindre enn vanlig       Mindre enn vanlig       Samme som vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i det hele tatt       Ikke mer enn vanlig       Heller mer enn vanlig         Ikke i



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### Andre helseplager

45. Oppgi i hvilken grad du har vært plaget av	lkke	Litt	En del	Alvorlig
Sett ett kryss for hver plage som er nevnt	plaget	plaget	plaget	plaget
Hjertebank, ekstraslag				
Brystsmerter				
Pustevansker				
Sure oppstør, "halsbrann"				
Sug eller svie i magen				
Løs avføring, diaré				
Forstoppelse				
Eksem				
Tretthet				
Svimmelhet				
Angst				
Nedtrykt, depresjon				

## Takk for hjelpen!



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# En undersøkelse om symptomer og plager i allmennpraksis

### Kjære pasient!

Målet med denne spørreundersøkelsen er å beskrive forekomsten av plager og symptomer hos voksne pasienter i allmennpraksis. Vi er spesielt opptatt av plager uten sikker medisinsk årsak. Erfaring viser at mange pasienter ikke forteller legen om alle plagene sine. Økt kunnskap om slike plager vil kunne bidra til at legen forstår pasienten bedre og dermed også kan hjelpe pasientene bedre.

Vi håper derfor at du kan hjelpe oss ved å delta i studien. Deltagelse i spørreundersøkelsen er selvsagt frivillig. Det er viktig at både dere som har mange plager og dere som har få eller ingen plager svarer. Det tar ca 5 minutter å fylle ut spørreskjemaet. Ved å fylle ut og sende inn skjemaet samtykker du i å være med i undersøkelsen. Du samtykker også i at resultatene publiseres i blant annet vitenskapelige artikler, og til at vi kan koble din og legens besvarelse.

Du bes helst fylle ut spørreskjemaet på venteværelset, og levere det i vedlagte konvolutt til legesekretæren før du går. Hvis du ikke har anledning til dette, kan du ta skjemaet med hjem og sende det til oss senere. Porto er betalt. Spørreskjemaet spør ikke om navn eller fødselsnummer, kun om kjønn og fødselsår. Du vil dermed være helt anonym.

Fastlegen din vil fylle ut et skjema om sin kjennskap til symptomene og plagene dine. Legen vil ikke kunne se besvarelsen din. Forskerne kan senere sammenligne din og legens besvarelse da de er koblet via et nummer.

Undersøkelsen utgår fra Universitetet i Oslo, avdeling for allmenn- og samfunnsmedisin, ved professorene Dag Bruusgaard og Jørund Straand og seniorforsker Bård Natvig.

Er det noe du lurer på, kan du ta kontakt med oss på telefon 22 850 558/900 96 722 eller på e-postadresse: hedda.tschudi-madsen@medisin.uio.no

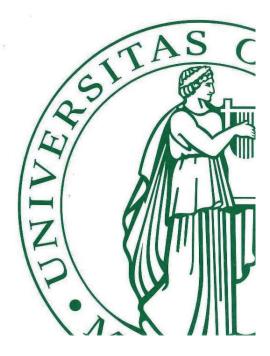
Vår adresse er:

Institutt for allmenn- og samfunnsmedisin, pb.1130 Blindern, N-0318 Oslo.

### Vi vil på forhånd takke for innsatsen!

Vennlig hilsen

Hedda Tschudi-Madsen allmennlege/forsker Mona Kjeldsberg spes. allmennmedisin/forsker



1. Kjønn	2. Fødselsår	Fødselsår		
Mann	19			

### 3. Sivilstatus

Gift/samboende	
Separent/skilt	
Enke/enkemann	
Enslig	

### 4. Utdanning, sett kryss ved den høyeste utdanningen du har til nå

Grunnskole
Videregående skole
Høyskole eller universitet (1-4 år)
Høyskole eller universitet (> 4 år)

### 5. Yrkesstatus

Yrkesaktiv	
Yrkesaktiv men sykemeldt	
Under utdanning	
Hjemmeværende	
Arbeidsledig	
RehabiliteringL	
Uføretrygdet	
PensjonertL	

### 6. Daglige aktiviteter

Har du siste 7 døgn hatt vansker med å utføre vanlige gjøremål eller oppgaver enten innendørs eller utendørs pga fysisk eller psykisk helse?

		•
lkke vansker i det hele tatt	Å	
Bare lette vansker		
Til en viss grad		
En god del vansker	Â	
Har ikke greid noe	<u>s</u>	

Sett kryss her

### 7. Samlet helsetilstand

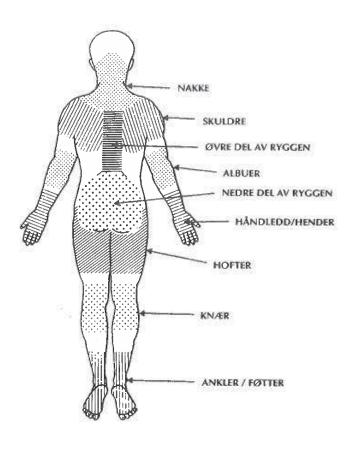
Hvordan vil du vurdere din egen helse fysisk og psykisk i alminnelighet de siste 7 døgn?

Sett kryss her

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8. Har du de siste 7 dager vært plaget av smerter/ ubehag noen av følgende steder? (kryss av for ja eller nei for hver kroppsdel)

	Ja	Nei
Hodet	$\Box$	
Nakken		
Håndledd/hender	$\Box$	
Øvre del av ryggen	$\overline{\Box}$	
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Knær	$\overline{\Box}$	$\square$
Ankler/føtter	$\Box$	



### 9. Har du i løpet av de siste 7 døgn vært plaget av noe av det følgende? (kryss i ruten)

Infeksjon, forkjølelse
Hjertebank/ekstraslag
Brystsmerter
Pustevansker/følelse av ikke å få nok luft
Sug eller svie i magen/halsbrann
Forstoppelse
Tarmgass, oppblåst
Løs avføring, diaré
Kvalme, oppkast
Hetetokter, svette
Kalde hender/føtter
Konsentrasjonsproblemer
Nedsatt hukommelse
Tretthet, utmattelse

### 10. Nedenfor har vi listet opp flere lidelser. Har du, eller har du vurdert om du kan ha en eller flere av følgende?

Amalgamforgiftning	
Candida-syndrom	]
El. overfølsomhet	
Fibromyalgi	

Kronisk utmattelsessyndrom(CFS/ME)[	
Matvareintoleranse	
Utbrenthet, «møtt veggen»	
Irritabel tarm	

### 11. Opplever du at noen av følgende forhold har negativ innvirkning på helsen din i dag?

Arbeidsbelastning, arbeidssituasjon	
Opplevelser i barndom/ungdom	
Familiære forhold	
Økonomiske forhold	

Andre alvorlige livshendelser	
Kosthold	
Lite fysisk aktivitet	
Røyking	
Alkohol	. 🗆

Da er du ferdig. Putt skjemaet i konvolutten og lever det i ekspedisjonen på legesenteret før du går. (Hvis du ikke får tid nå, kan du sende det til oss senere).

Tusen takk for hjelpen!

Har du noen kommentarer til spørreskjemaet eller undersøkelsen?



# En undersøkelse om symptomer og plager i allmennpraksis

Målet med denne spørreundersøkelsen er å kartlegge forekomsten av symptomer og plager hos voksne pasienter i allmennpraksis. Pasienter med mange symptomer der det kan være vanskelig å stille en sikker diagnose er en utfordring for helsevesenet generelt og allmennpraksis spesielt. Det er lite kunnskap om slike plager i Norge. Økt kunnskap vil kunne bidra til at legen kan hjelpe pasientene bedre, og forskning på dette feltet er anbefalt av Legeforeningen.

Vi håper derfor at du kan hjelpe oss ved å delta i undersøkelsen. Deltakelse i studien er selvsagt frivillig for både lege og pasient. Dersom du fyller ut og sender inn skjemaene, samtykker du i å delta i undersøkelsen. Du samtykker også i at resultatene publiseres, blant annet i vitenskapelige tidsskrifter, og i at vi kan koble din og pasientens besvarelse.

- Du bes inkludere 20 fortløpende pasienter over 18 år som konsulterer deg i løpet av én til to arbeidsdager.
- Mot slutten av konsultasjonen spør du pasienten om han/hun er villig til å delta i en enkel spørreundersøkelse om plager og symptomer.
- Pasienten får med seg spørreskjema og skriftlig informasjon. De bes fylle ut skjema, helst på venteværelset, men kan eventuelt ta det med hjem. Skjemaet kan leveres til legesekretær før pasienten går eller sendes i frankert konvolutt senere.
- Før neste pasient tas inn, fyller du ut et korresponderende skjema om pasienten. Det tar et par minutter å fylle ut hvert skjema. Dersom du ikke rekker å fylle ut skjemaet underveis, kan du evt. fylle det ut ved slutten av dagen, men vi ber da om at du uansett fyller inn fødselsår og kjønn umiddelbart etter konsultasjonen.
- Skjemaene dine returnerer du samlet i vedlagte frankerte svarkonvolutt.

Hverken lege- eller pasientskjema inneholder pasientens navn eller fødselsnummer, kun kjønn og fødselsår. Det blir ikke spurt om personlige opplysninger om legen. Skjemaene er merket med et nummer, slik at vi senere kan koble pasientens og legens besvarelser.

Undersøkelsen utgår fra Universitetet i Oslo, avdeling for allmenn- og samfunnsmedisin, ved professorene Dag Bruusgaard og Jørund Straand og seniorforsker Bård Natvig.

Er det noe du lurer på kan du ta kontakt med oss på telefon 22 85 05 56/900 96 722 eller på e-postadresse: hedda.tschudi-madsen@medisin.uio.no

### Vår adresse er:

Institutt for allmenn- og samfunnsmedisin, pb.1130 Blindern, N-0318 Oslo.

### På forhånd takk for hjelpen!

Vennlig hilsen

Hedda Tschudi-Madsen allmennlege/forsker Mona Kjeldsberg spes. allmennmedisin/forsker



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### 8. Vurderer du at noen av følgende forhold har negativ innvirkning på pasientens helse i dag?

Arbeidssituasjon/arbeidsbelastning
Opplevelser i barndom/ungdom
Familiære forhold
Andre alvorlige livshendelser

Kosthold	
Lite fysisk aktivitet	
Røyk	
Alkohol	

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### Patients in general practice share a common pattern of symptoms that is partly independent of the diagnosis

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RESEARCH ARTICLE

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# Patients in general practice share a common pattern of symptoms that is partly independent of the diagnosis

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#### ABSTRACT

**Objective:** To describe self-reported symptoms among patients in general practice and to explore the relationships between symptoms experienced by patients and diagnoses given by general practitioners.

**Design:** Doctor-patient questionnaires focusing on patients' self-reported symptoms during the past 7 days and the doctors' diagnoses.

Setting: General practices in urban and suburban areas in Southeast Norway.

**Subjects:** Forty-seven general practitioners who included 866 patients aged  $\geq$ 18 years on a random day in practice.

**Results:** The most frequently reported symptoms were tiredness (46%), lower back pain (43%), neck pain (41%), headache (39%), shoulder pain (36%), and sleep problems (35%). Women had a significantly higher prevalence than men for 16 of 38 symptoms (p < 0.05). The mean number of symptoms was 7.5 (range, 0–32; women, 8.1; men, 6.5, p < 0.05). Regression analysis showed that patients who received a social security grant had 59% more symptoms than those who were employed and that people with asthenia and depression/anxiety had 44% and 23% more symptoms, respectively than those with all other diagnoses. The patterns of symptoms reported showed similar patterns across the five most prevalent diagnoses.

**Conclusions:** Patients in general practice report a number of symptoms and share a common pattern of symptoms, which appear to be partly independent of the diagnoses given. These findings suggest that symptoms are not necessarily an indication of disease.

#### **KEY POINTS**

- Patients consulting general practitioners have a high number of self-reported symptoms.
- The most frequent symptoms are tiredness, lower back pain, neck pain, headache, shoulder pain, and sleep problems.
- Patients diagnosed with asthenia and depression/anxiety report the highest number of symptoms.
- Selected diagnoses show similar patterns in symptom distribution.
- Symptoms are not necessarily an indication of disease.

#### Introduction

The presentation of symptoms is the patient's first step in the communication with the general practitioner (GP) in the consultation. However, the healthcare-seeking behaviour of patients does not necessarily reflect the severity of their symptoms. There is a known discrepancy between the full range of symptoms experienced by patients and the symptoms they choose to present to their doctor [1].

How a symptom is interpreted by a person depends on individual factors and preconceptions.

The intensity and duration of the symptoms, and the person's evaluation of the seriousness of the symptoms are central factors in the decision to consult a medical practitioner [2]. The factors that ultimately trigger consultation with a GP vary greatly between patients.

GPs can only evaluate concerns or symptoms presented by the patient. Only 5–25% of people contact a GP because of a symptom [1]. This implies that only a selection of the symptoms is deemed alarming or bothersome enough to motivate the patient to

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#### **KEYWORDS**

Self-report; symptom reporting; social security grant; questionnaire; general practice

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consult a doctor [3]. Even among people with symptoms that could indicate a serious disease, such as blood in the urine, shortness of breath, or coughing blood, only half contact their GP about that symptom [4]. On the other hand, GPs tend to overestimate to what extent their patients consult them for minor medical problems [5].

There is a known discrepancy between the full range of symptoms experienced by patients and the symptoms they choose to present to the doctor [1]. Among patients who disclose, before the consultation, that they have symptoms they intend to discuss with their GP, 23% of the symptoms [6] and up to 25% of patient concerns are not mentioned during the consultation [7]. By contrast, people who consider themselves healthy may report a higher number of symptoms [8]. In most patients who undertake a routine check-up in general practice and who initially declare that they did not have any symptoms, symptoms were found to constitute a major part of their agenda [9].

The commonly used definitions of symptoms relate symptoms to health problems or disease [10]. The WONCA Dictionary of General/Family Practice describes symptoms as, 'any subjective evidence of a health problem as perceived by the patient' [11]. Labelling a health problem can result in a disease diagnosis, such as diabetes, or may result in a symptom diagnosis, such as lower back pain or fatigue, both of which group patients under a label describing the main symptom according to the International Classification of Primary Care (ICPC) [12].

Understanding of the process from first experiencing a symptom to receiving a diagnosis is limited. Disentangling the various roles of symptoms in making a diagnosis represents a challenge, and symptoms selected by the patient for presentation to the GP may or may not provide clues relevant to making the diagnosis. Whether a presented symptom will contribute to the final diagnosis depends on whether the GP finds the symptom relevant during the consultation. Although the diagnoses given by GPs have been found to correspond well with their notes about the patient recorded during consultations [13], the diagnoses reflect only the symptoms that are communicated. Other symptoms that are not communicated, commonly referred to as the 'submerged' part of a symptom 'iceberg', may not be considered [14,15].

More than 20 years ago, Kroenke noted that more diagnostic information may be collected from a patient's symptom account than from the physical examination [16]. Since then, an increasing number of

studies of symptoms have been conducted, but these have focused mainly on symptom prevalence. More recently, it has been acknowledged that both the type and number of symptoms can provide important information about the patient [17]. Counting symptoms, an approach that has been used to study the relationship between functional ability and health in the population, has shown that reporting a high number of symptoms is associated with an increased risk of reporting poor health [18] and may predict future disability benefits [19], irrespective of the type and severity of the symptoms [18,19]. It has also been shown that the number of symptoms may provide more information about future health outcomes than the diagnosis given [20]. These findings suggest that counting symptoms may be a valuable tool in general practice.

We conducted a survey among GPs and their patients in which we focused on symptoms, diagnoses, and function. Our aims were to map the occurrence of a range of common symptoms in patients, regardless of the reasons for the consultation, and to explore the associations between the patient-reported symptoms and the GP-recorded main diagnosis.

### Method

We recruited GPs from meetings with counselling groups for doctors seeking to become specialists in general practice in urban and suburban areas in Southeast Norway. The inclusion period was from June 2010 to January 2012. After a brief introduction to our study, 47 GPs agreed to participate. The GPs were asked to include all consecutive patients regardless of their reason for the encounter, adding up to  $\geq$ 20 patients aged  $\geq$ 18 years seen on a random day of practice during the following 2 weeks. If the GP saw <20 patients on a practice day, the inclusion should continue the next practice day. At the end of each consultation, the GPs asked their patients to complete a questionnaire. The patients orally consented to participate after reading the letter accompanying the survey.

The questionnaires for both the GPs and the patients were completed separately directly after the consultation. The answers were linked by serial numbers. A pilot study was first conducted to validate and adjust the questionnaires.

#### Dependent variables

The patients were asked whether during the previous week they had experienced any of 38 common

**Table 1.** Distribution of the 38 symptoms reported in general practice for the past 7 days for the total sample and for women and men separately.

		Total	Women	Men
		(n = 866)	(n = 559)	(n = 307)
Symptoms	п	%	%	%
Tiredness	378	43.6	45.1	41.0
Lower back pain	368	42.5	43.1	41.4
Neck pain	358	41.3	47.0	30.9
Headache	335	38.7	43.1	30.6
Shoulder pain	308	35.6	40.1	27.4
Sleep problems	303	35.0	38.3	29.0
Infection	238	27.5	26.5	29.3
Hand/wrist pain	232	26.8	28.8	23.1
Knee pain	220	25.4	25.9	24.4
Cold hands/feet	202	23.3	25.9	18.6
Problems concentrating	199	23.0	24.7	19.9
Ankle/foot pain	197	22.7	23.8	20.8
Upper back pain	196	22.6	24.7	18.9
Dizziness	193	22.3	26.5	14.7
Flatulence/bowel gas	189	21.8	25.0	16.0
Hip pain	184	21.2	24.3	15.6
Anxiety	166	19.2	20.4	16.9
Depression	166	19.2	20.6	16.6
Eczema	157	18.1	17.7	18.9
Hot flushes	152	17.6	20.6	12.1
Diarrhoea	147	17.0	17.7	15.6
Heart burn/dyspepsia	146	16.9	19.0	13.0
Memory problems	143	16.5	17.4	15.0
Dry eyes	137	15.8	17.7	12.4
Breathing difficulties	134	15.5	16.8	13.0
Palpitations	120	13.9	15.9	10.1
Tinnitus	114	13.2	10.4	18.2
Leg cramps	111	12.8	13.6	11.4
Elbow pain	98	11.3	11.8	10.4
Chest pain	92	10.6	8.8	14.0
Vomiting	87	10.0	12.0	6.5
Fasciculation/twitches	82	9.5	8.1	12.1
Allergy	79	9.1	10.9	5.9
Oedema	79	9.1	10.6	6.5
Urinary problems	70	8.1	6.8	10.4
Constipation	69	8.0	10.6	3.3
Sight problems	47	5.4	6.1	4.2
Fainting	16	1.8	1.3	2.9

Note. The symptoms are listed in descending order of overall prevalence. Bold values indicate a significantly higher prevalence of a symptom (p < 0.05) in one sex. *p*-Values were calculated using the Chi-squared test.

symptoms included in a symptom check-list without regard to whether the symptoms were discussed with the GP. The list of symptoms comprised 10 pain symptoms from the Standardised Nordic Questionnaire [21] and 28 symptoms from the Subjective Health Complaints Inventory [22] (Table 1). The dependent variables were the sum score of symptoms and the individual symptoms.

#### Independent variables

From the GP questionnaire, we used only information about the diagnosis and possible chronic conditions. The GPs were asked to register the main diagnosis (only one) by using codes from the second edition of the ICPC (ICPC-2) or by written text, the latter of which two authors (MK and HTM) had labelled with ICPC-2 codes before the analyses. The total number of reported ICPC-2 codes was 321. If more than one main diagnosis was given, which was the case in five of the questionnaires, the first diagnosis written was used. We selected the most frequent single diagnoses for further analyses: asthenia (ICPC A04), diabetes (T89, T90), depression/anxiety (P01, P03, P74, P76), hypertension (K85, K86) and lower back pain (L02, L03, L84, L85).

The GPs were also asked to report whether or not the patient had, in addition to the current diagnosis, one or more prevalent chronic conditions from the following nine diagnostic categories: cardiovascular, respiratory, cancer, musculoskeletal, endocrinological, gastroenterological, psychological, neurological, and other. A sum score of 0, 1, 2, and 3+ prevalent chronic conditions was created. The GP questionnaire contained no questions about the symptoms reported by the patient.

In addition to the symptom checklist, the patient questionnaire included questions about the patients' sex, age, civil status, educational level, and employment status. Age was pooled into the age categories 18–29, 30–39, 40–49, 50–59, 60–69, and 70+ years. Civil status was grouped into married, separated, widowed, and single. Educational level was registered as  $\leq$ 10 years, 11–13 years, university (1–4 years), and university (>4 years). Employment status was categorized as employed, social security grant for  $\leq$ 1 year, social security grant for >1 year, and retired.

#### Statistical methods

Frequencies and percentages were used to describe the prevalence of symptoms. The numbers of symptoms were summarized using means, and differences in means between two categories of a nominal variable were identified using the independent *t*-test. One-way analysis of variance (ANOVA) with a Tukey post hoc test was used to compare the mean number of symptoms of a nominal variable with  $\geq$ 3 categories.

We selected the five most prevalent diagnoses and clustered the rest into 'other', which we used as the reference category.

We also modelled the number of symptoms using a Poisson regression model and obtained estimates (incidence rate ratios; IRRs) of the association between each of several possible socio-demographic, diagnosis and condition-count predictors, adjusted for all other

**Table 2.** Mean distribution of the number of symptoms reported in the past 7 days by patients consulting their GP.

Factors	n	Mean (95% CI)	<i>p</i> -Values <sup>*</sup>
Sex (ref.: Men)			
Men	307	6.5 (5.9, 7.1)	
Women	559	8.1 (7.6, 8.6)	< 0.01
Age group (ref.: 18–29)			
18–29	153	6.7 (6.0, 7.5)	
30–39	165	7.1 (6.3, 7.9)	0.61
40–49	160	8.4 (7.4, 9.3)	0.01
50–59	142	8.8 (7.7, 9.9)	< 0.01
60–69	128	6.9 (6.0, 7.8)	0.77
70+	118	7.2 (6.2, 8.1)	0.54
Civil status (ref.: Married)			
Married	575	7.0 (6.6, 7.4)	
Separated	90	9.3 (8.0, 10.6)	< 0.01
Widow(er)	45	8.3 (6.7, 9.9)	0.14
Single	156	8.2 (7.3, 9.2)	0.02
Educational level in years (ref.: $\leq$ 10)			
<u>≤</u> 10	149	7.8 (6.9, 8.7)	
11–13	323	7.9 (7.3, 8.5)	0.87
University (1–4)	240	7.3 (6.6, 8.0)	0.41
University (>4)	154	6.8 (5.9, 7.7)	0.11
Employment status (ref.: Employed)			
Employed	456	6.1 (5.7, 6.6)	
Social security grants (<1 year)	121	9.5 (8.5, 10.5)	< 0.01
Social security grants (>1 year)	133	11.4 (10.3, 12.6)	< 0.01
Retired	156	6.7 (5.9, 7.5)	0.25
Selected diagnoses (ref.: Other)			
Asthenia	34	11.2 (9.1, 13.2)	<0.01
Diabetes	27	6.3 (3.8, 8.9)	0.34
Depression/anxiety	37	10.7 (8.7, 12.7)	<0.01
Hypertension	56	5.6 (4.5, 6.7)	0.02
Lower back pain	23	8.0 (5.7, 10.3)	0.58
Other	689	7.4 (6.9, 7.8)	
Prevalent chronic conditions (ref.: None)			
None	306		
1	307		0.03
2	163	8.6 (7.6, 9.5)	<0.01
3+	90	10.1 (8.9, 11.3)	<0.01

\*ANOVA and a post hoc test were used to identify differences between the categories within the variables.

predictors in the model. Poisson regression is a convenient model for estimating the association between the number of symptoms reported and various factors like age or diagnosis; the association is expressed as incidence rate ratios (IRR), which represents the change in the number of symptoms in one group relative to the change in the reference group. We fitted three separate Poisson regression models to our data and selected the best model by using the Bayesian information criterion (BIC), which states that the model with the smallest BIC should be selected.

While it is a common practice to model associations with a dichotomous outcome via a binary logistic regression model, the argument for interpreting the odds ratios (ORs) as relative risks (RRs) holds true only in cases where the outcome is rare (prevalence is  $\leq$ 10%). Since the prevalence of common symptoms in studies is usually high (>10%) and with 38 symptoms to investigate, the RR, which we used as a descriptive statistic rather than an inferential statistic was preferred above OR to describe associations with our

dichotomous outcome. The RR was estimated by dividing the probability of having a symptom given a diagnosis by the probability of having the same symptom if the diagnosis is not given (referent). Because the RR is a ratio of two probabilities, it follows that (1) assumptions regarding probability estimation in each group holds and (2) that the probability of having a symptom given a diagnosis in the reference group is >0. RR estimates and their 95% confidence intervals (Cls) are presented in a forest plot. Only the symptoms with significant Cls for RR are presented.

IBM SPSS Statistics 26 and Stata/SE 16 were used to analyse the data. The significance level was set at  $\alpha = 0.05$ .

### Results

In total, 1024 questionnaire pairs were distributed; 909 patient questionnaires were returned, and 866 had a corresponding answer from the doctor, giving an overall response rate of 84.6%. The mean age was 48.3 years (women, 47.2; men, 50.2 years), and 64.5% of responders were women.

The most frequent symptoms reported during the past week were tiredness (43.6%), lower back pain (42.5%), neck pain (41.3%), headache (38.7%), shoulder pain (35.6%), and sleep problems (35.0%). Women had a significantly higher prevalence than men of 16 of 38 symptoms (p < 0.05). Only chest pain and tinnitus (p < 0.05) were more commonly reported by men (Table 1).

The number of symptoms reported by each patient ranged from 0 to 32 (out of 38 possible). At least one symptom was reported by 97%, >10 symptoms were reported by 29.2%, and >15 symptoms were reported by about 1%. The overall mean number of symptoms was 7.5 (men, 6.5; women, 8.1) (p < 0.01). The highest mean number of symptoms (11.4) was found in patients receiving a social security grant >1 year. Patients aged 40-49 and 50-59 years reported more symptoms than those younger or older, and those with a chronic condition reported more symptoms than those without a chronic condition. Among the selected diagnoses, patients with hypertension reported fewer symptoms (5.6), whereas those with asthenia (11.1) and depression/anxiety (10.7) reported significantly more symptoms than did patients with all other diagnoses (Table 2).

In the adjusted Poisson regression model, women reported 21% more symptoms than men (Table 3). The age groups 40–49 years and 50–59 years had 17% and 19% more symptoms than the youngest age

	Unadjuste	ed	Adjusted		
Factors	IRR (95% CI)	<i>p</i> -Values	IRR (95% CI)	p-Values	
Sex (ref.: Men)					
Women	1.24 (1.18, 1.31)	< 0.01	1.21 (1.15, 1.28)	<0.01	
Age groups (ref.: 18–29)					
30–39	1.05 (0.96, 1.14)	0.28	1.04 (0.95, 1.13)	0.42	
40–49	1.24 (1.14, 1.35)	< 0.01	1.17 (1.08, 1.27)	< 0.01	
50–59	1.30 (1.20, 1.42)	< 0.01	1.19 (1.09, 1.30)	< 0.01	
60–69	1.03 (0.94, 1.12)	0.54	0.96 (0.86, 1.06)	0.38	
70+	1.06 (0.97, 1.16)	0.19	1.10 (0.95, 1.27)	0.21	
Employment status (ref.: Employed)					
Social grants $<1$ year	1.55 (1.45, 1.66)	< 0.01	1.44 (1.34, 1.55)	<0.01	
Social grants $>1$ year	1.87 (1.75, 1.99)	< 0.01	1.59 (1.48, 1.71)	< 0.01	
Retired	1.09 (1.02, 1.17)	0.02	1.04 (0.91, 1.18)	0.58	
Selected diagnoses (ref.: All other)					
Asthenia	1.52 (1.37, 1.68)	< 0.01	1.44 (1.29, 1.60)	< 0.01	
Diabetes	0.86 (0.74, 1.00)	0.05	0.97 (0.83, 1.14)	0.72	
Depression/anxiety	1.46 (1.32, 1.62)	< 0.01	1.23 (1.10, 1.36)	< 0.01	
Hypertension	0.76 (0.68, 0.85)	< 0.01	0.74 (0.66, 0.84)	< 0.01	
Lower back pain	1.09 (0.94, 1.26)	0.26	1.15 (0.99, 1.33)	0.07	
Prevalent chronic conditions (ref.: 0)					
1	1.02 (0.94, 1.11)	0.66	0.99 (0.91, 1.08)	0.83	
2	1.15 (1.06, 1.26)	< 0.01	1.09 (0.99, 1.19)	0.07	
3+	1.46 (1.33, 1.59)	< 0.01	1.36 (1.23, 1.51)	< 0.01	

**Table 3.** Estimates of incidence rate ratios (IRRs) and their 95% confidence intervals (CIs) obtained from the Poisson regression model showing socio-demographic factors and diagnoses given by GPs that were significantly associated with the number of symptoms reported in the past 7 days.

Note. Three separate adjusted Poisson models were fitted to the data for the numbers of symptoms using the Poisson regression models: Model 1: (Bayesian information criterion (BIC) 6028) sex, age, civil status, educational level, employment status, selected diagnoses, chronic conditions (not shown); Model 2: (BIC 6020) sex, age, educational level, employment status, selected diagnoses, chronic conditions (not shown); and Model 3: (BIC 6004) sex, age, employment status, selected diagnoses, chronic conditions (not shown); and model 3: (BIC 6004) sex, age, employment status, selected diagnoses, chronic conditions. Model 3 (Table 4) was chosen because it has the smallest BIC.

group. Patients who had received a social security grant for >1 year had 59% more symptoms than those who were employed. Having three or more prevalent chronic conditions was associated with 36% more symptoms compared with those having no chronic condition. Patients with asthenia and depression/anxiety diagnoses reported 44% and 23% more symptoms, respectively, compared with patients with 'all other' diagnoses, whereas patients with hypertension reported 26% fewer symptoms. Patients with lower back pain and diabetes did not differ significantly from those with 'all other' diagnoses when comparing the number of symptoms.

Figure 1 shows the prevalence of the individual symptoms for the five selected diagnoses compared with the total prevalence of symptoms in the study population. The symptoms are presented in descending order of total prevalence. The prevalence rates of the diagnoses of lower back pain, depression/anxiety, and asthenia showed symptom patterns with the same prevalence of symptoms as the total. Hypertension and diabetes followed the total prevalence of the symptoms closely, except for four and two of the 38 symptoms, respectively.

The RR of having each of the symptoms given one of the diagnoses compared with the RR of having the symptoms in those not having the diagnosis is shown in a forest plot (Table 4). In this table, only symptoms with an RR significantly different from 1 are presented.

Of the 38 symptoms, increased RRs were found for 13 symptoms in patients diagnosed with asthenia, 12 symptoms in those with depression/anxiety, three symptoms in those with lower back pain, one symptom in those with diabetes, and one symptom in those with hypertension. For the rest of the symptoms, no increased RR was found in patients with a diagnosis compared with those without the diagnosis.

We found only small variations in symptom patterns according to age and sex (data not shown).

### Discussion

#### Summary of the main findings

Patients in general practice reported a mean of 7.5 symptoms during the week before the consultation. Tiredness, lower back pain, neck pain, headache, shoulder pain, and sleep problems were the most prevalent symptoms. Patients receiving a social security grant and being diagnosed with asthenia or depression/anxiety reported the most symptoms. The prevalence of the symptoms showed similar patterns across the most prevalent diagnoses.

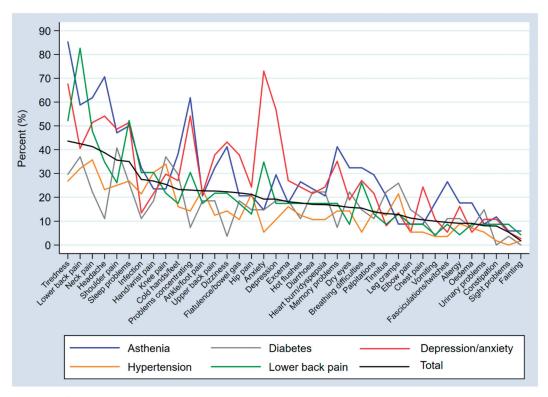


Figure 1. Prevalence of individual symptoms according to the selected diagnoses compared with the total prevalence of symptoms in the study population.

#### Strengths and weaknesses of the study

The survey was conducted among consecutive patients seen in general practice. The group of patients is representative of Norwegian adults in terms of age and sex distribution [23], except for slightly more respondents aged 30–49 and slightly fewer older than 70 years. The response rate was high, and the number of participating doctors was acceptable.

The participating GPs were recruited from counselling groups that were part of a postgraduate education required to become a specialist GP. Therefore, the doctors had limited experience. As is the case for most similar studies, the willingness to participate could have led to a selection of GPs with a particular interest in research on symptoms. Awareness of the study may have influenced the GPs in their diagnostic attribution. As we did not focus on outcome measures in meetings with the groups, this potential bias should be minor. The GPs were asked to include consecutive patients on a day in practice, but we do not know whether or how often the GPs forgot to hand out a questionnaire.

The GPs were asked to record only the main diagnosis in the consultation but, for five patients, more than one diagnosis was registered. In retrospect, we should have provided an opportunity to register more than one diagnosis. Although there has been an increased focus on research on symptoms in recent years, the studies conducted vary in both type and number of symptoms included, and in the inclusion period, which makes comparisons difficult [20,24]. There is no common questionnaire that could facilitate comparisons. In this study, we created the patient questionnaire by merging two commonly used questionnaires.

We did not consider the intensity of symptoms, but previous research has shown that even symptoms considered to be less bothersome are important to self-reported health and functional ability [18].

Our main objective was to map the occurrence of symptoms among patients and to compare these with a number of factors, including the diagnoses given by the doctor. We did not record which symptoms were presented to the GP during the consultation.

An important limitation of our study was the low prevalence of each diagnosis. We, therefore, selected the five most frequent diagnoses for further analysis.

### Findings in relation to other studies

Studies both among patients in general practice and the general population have shown that tiredness, musculoskeletal symptoms, and headache are among the most reported symptoms [1,14,25,26], as we found in our study.

	Non-cases	Cases	:	RR [95% CI]
Astenia				
-asciculations/ twitches	25	9		3.02 [1.65, 5.52]
Problems concentrating	13	21		2.89 [2.15, 3.88]
lemory problems	20	14		2.66 [1.72, 4.10]
Palpitations				2.22 [1.28, 3.85]
Breathing difficulties	24	10		
	23	11		2.19 [1.31, 3.66]
Dry eyes	23	11		2.14 [1.28, 3.57]
iredness	5	29	┝╋┤	2.03 [1.73, 2.39]
Dizziness	20	14	├■	1.91 [1.25, 2.92]
leadache	10	24	┝╼┤	1.89 [1.49, 2.39]
Cold hands/ feet	21	13	├■	1.68 [1.08, 2.62]
leck pain	13	21		1.52 [1.15, 2.00]
Sleep problems	17	17		1.45 [1.03, 2.05]
ow back pain	14	20	<b>⊢</b> -■1	1.41 [1.05, 1.89]
	14	20	1 - 1	[]
Depression/ anxiety				
Anxiety	10	27	⊢∎⊣	4.35 [3.40, 5.57]
Depression	16	21	-∎-	3.24 [2.36, 4.45]
Problems concentrating	17	20	-∎	2.50 [1.81, 3.46]
leck pain	28	9	₽	2.43 [1.33, 4.44]
lemory problems	24	13		2.24 [1.41, 3.56]
Dizziness	21	16		2.03 [1.37, 3.00]
Breathing problems	27	10		1.81 [1.04, 3.15]
latulence/ bowel gas	23	14		1.79 [1.16, 2.76]
Jpper back pain	23	14		1.72 [1.12, 2.65]
Tiredness	12			1.59 [1.25, 2.02]
		25		
Sleep problems	18	19		1.50 [1.08, 2.08]
leadache	17	20	┠╼┻╌┤	1.42 [1.04, 1.94]
ow back pain.				
ow back pain	4	19	<b>⊢</b> ∎-1	2.00 [1.63, 2.45]
Anxiety	15	8	· · · ·	1.86 [1.04, 3.31]
Sleep problems	10	12		1.51 [1.01, 2.26]
	11	12		1.01 [1.01, 2.20]
lypertension				
.eg cramps	44	12	<b>}−−−</b> 1	1.75 [1.03, 2.98]
Anxiety	53	3	├	0.27 [0.09, 0.81]
leadache	43	13	<b>⊢∎</b>	0.58 [0.36, 0.94]
īredness	41	15	∎	0.60 [0.39, 0.93]
Diabetes				
	00	7	_	2.09 [1.08, 4.05]
eg cramps	20	7		
leadache	24	3	▶	0.28 [0.10, 0.80]
		0.05	0.37 1 2.72 7.39	
		0.00	Relative Risk (RR)	

Table 4. Relative risk (RR) estimates showing the likelihood of patients reporting the individual symptoms in the past 7 days according to the most prevalent diagnoses given by their GP.

Note. Non-cases and cases refers to patients' not reporting and reporting symptoms, respectively. RRs and their 95% confidence intervals (Cls) to the right of the vertical line (dotted) in the forest plot represent an increase in the likelihood of having a particular symptom, whereas RRs to the left of the vertical line represent a decrease in the likelihood. Only the symptoms with statistically significant Cls are shown in the plot.

The mean number of symptoms reported was 7.5; in our previous population study, we found the mean number of symptoms was 6.0 [27]. This difference may reflect that the population study including fewer symptoms (22 versus 38). However, one would expect a higher number of symptoms to be reported by people who visit a GP than in population surveys.

Our finding that women reported more symptoms than men is consistent with the results from other studies [1,14,25,26], although the sex difference was significant only for 16 of the 38 symptoms in our study. This sex difference was similar to that found in our population study, with 25% more symptoms in women in our study and 31% more in our previous study [27].

In our study, the middle-aged participants reported more symptoms than the younger and older age groups. This result differs from those of some previous studies [26], but is consistent with the results in large population-based studies [2,14].

Patients receiving a social security grant reported the highest number of symptoms. Presenting many symptoms is known to be strongly associated with low functional status and high rates of absence from work [18,19,28]. Hence, experiencing many symptoms may be considered a sign of impaired health.

As expected, the mean number of symptoms increased with an increasing number of chronic conditions [14]. The differences in the number of symptoms among the most prevalent diagnoses are clinically explainable. Patients with the diagnoses asthenia and depression/anxiety report a high number of symptoms. Asthenia (A04) is a symptom diagnosis according to ICPC-2 and may be used for tiredness/asthenia symptoms alone. However, asthenia is also associated with medically unexplained symptoms [25], which in turn are strongly associated with the reporting of multiple symptoms [29]. Mental health problems are also associated with a high number of symptoms [30]. Diabetes can result in complications in several different organs, but diabetes patients in general practice are often in an early stage, have few diagnosis-specific symptoms, and report good health [31]. Hypertension among general practice patients is as much an asymptomatic risk factor as a disease diagnosis, and most patients with hypertension also rate their health as good [32]. In our study, participants with hypertension had fewer symptoms than the overall mean.

There is often a discrepancy between the experienced symptoms and the symptoms that are revealed in a medical consultation [15]. Although we did not collect information about which symptoms were presented to the GP during the consultation, we have reason to believe that several symptoms were not presented because they may have been seen as irrelevant by the patient and not asked about by the doctor [1].

We have explored symptom patterns for the most prevalent diagnoses. We found differences in the patterns, especially for the diagnoses of depression/anxiety and asthenia, where almost one-third of the symptoms had an increased RR for being reported. These findings suggest some important and clinically expected differences between the diagnoses. However, despite the differences, the selected diagnoses seem to share a common pattern of symptoms. For most symptoms, the RRs in patients with a diagnosis did not differ significantly from those not having the diagnoses suggest that symptoms are not necessarily a sign of a particular disease.

Patterns of symptoms have previously been explored using factor analyses [22,33]. A recent Danish study by Eliasen et al. found a strong correlation between symptoms within certain categories, such as the musculoskeletal, gastrointestinal, and cardiopulmonary categories [34]. On the other hand, several studies have demonstrated a general factor that involves loadings from all symptoms. The findings of correlations between symptoms across body regions and organ systems [34,35] confirm that symptom patterns constitute a complex picture.

Reporting a high number of symptoms independent of the type or severity [18] may be indicative of a patient's future health status [36]. Patients experiencing a high number of symptoms with a high symptom concern or with symptoms that affect daily activities consult a GP more often [2], even though they may present only a selection of the symptoms in the consultation. Insight into the whole pattern of symptoms in patients might provide useful information for clinical evaluations by GPs about whether a patient's symptoms can be linked to a particular disease.

### Conclusion

Our results indicate that most patients report a variety of symptoms, and that these symptoms appear to be partly independent of the diagnoses given by their GP. Information about the total symptom load may provide a better understanding of the patient's needs. On the other hand, such information might complicate the diagnostic process because symptoms are not necessarily an indication of disease, contrary to what is implied in the existing definition of symptoms.

#### **Ethical approval**

The study was presented to the Ethics Board (The Regional Committee for Medical and Health Related Research Ethics in Western Norway) but was exempted from review. Research on anonymous data not collected by the researchers themselves are exempted.

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### **Disclosure statement**

The authors report no conflict of interests. The authors alone are responsible for the content and writing of the paper.

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### ERRATALISTE

Forkortelser for type rettinger:

Cor – korrektur

### Celtf - endring av sidelayout eller tekstformat

Side	Linje	Originaltekst	Type rettelse	Korrigert tekst
16	13	was most frequent among	Celtf	was frequent also among