Disability in patients entering rehabilitation centres in secondary care in Norway: A cross-sectional study of predictors and the relationships with sense of coherence and health-related quality of life.

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Thesis for the Degree of Philosophiae Doctor (PhD) University of Bergen, Norway 2018



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### Scientific environment

The work presented here is collaboration between Centre for Habilitation and Rehabilitation in the Western Norway Health Region, and the research group of health services at Department of Global Public Health and Primary Care, Faculty of Medicine at the University of Bergen.

Main supervisor was Sturla Gjesdal, professor at the Department of Global Public Health and Primary Care, while, Jorunn Drageset, professor at the Department of Global Public Health and Primary Care and Geir Egil Eide, professor at the Department of Global Public Health and Primary Care and biostatistician at Centre for Clinical Research at Haukeland University Hospital, were co-supervisors.

Additionally, Mari Klokkerud, unit manager and researcher, National Advisory Unit on Rehabilitation in Rheumatology, Diakonhjemmet hospital in Oslo, was co-author of Paper I.

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### **Abstract**

### Background

According to the World Health Organization 15% of the world's population has some form of disability, and rehabilitation is the main health strategy to target disability. There is limited knowledge about patients entering rehabilitation centres in secondary care in Norway. Age, sex, and referral health condition are reported by the health authorities. A national standard is lacking for measuring the main variable in rehabilitation: disability. Furthermore, targeting patients' resources so that they can gain better control over their life situations and improve their health status is emphasized for rehabilitation by the national health authorities.

The aim of this study was to increase the knowledge basis of health characteristics with respect to disability in patients entering rehabilitation centres in secondary care. To accomplish this, we aimed to clarify conceptual models of disability and how disability can be measured. Finally, with respect to clinical implications, we aimed to increase understanding of how to reduce disability and promote health.

The specific objective for the first part of this work was to evaluate the measurement properties of the Norwegian version of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) in Paper I. The second objective was to assess disability among rehabilitation patients and its predictors (Paper II). The third objective was to investigate the role of sense of coherence (SOC) and its relation to disability and health-related quality of life (HRQoL) in Paper III.

#### Materials and methods

This thesis is based on data from a cross-sectional study. All patients in the Western Norway Health Region that were accepted for inpatient or outpatient rehabilitation at a rehabilitation centre in secondary care during the first half of 2015, and who were referred from hospitals or general practitioners, were invited by mail or at admittance. Each patient completed a comprehensive questionnaire before entering the

rehabilitation centre. A randomised sample of patients invited by mail completed the WHODAS 2.0 a second time, within 5–15 days after the first completion to assess reproducibility (Paper I). To assess responsiveness of the WHODAS 2.0, another randomised sample completed the WHODAS 2.0 approximately 4–13 weeks after discharge from the rehabilitation centre. For definitions, taxonomy, and terminology, Consensus-based Standards for the selection of health status Measurement INstruments (COSMIN) was followed in Paper I and tests of reproducibility, construct validity and responsiveness were performed.

In Paper II, the distribution of disability was assessed using descriptive statistics. Sociodemographics and health variables were investigated as predictors for disability in regression analyses.

In Paper III, SOC was investigated as a predictor for disability in regression analysis, and two hypothesized models including SOC, disability, and HRQoL were examined using structural equation modelling.

#### Results

In Paper I, the intraclass correlation coefficient was 0.87 for total disability score, with a range of 0.63–0.84 for domain scores. For construct validity, 6 of 12 expected correlations were confirmed, and confirmatory factor analysis did not reach a satisfactory fit with the original structure. For responsiveness, three of eight hypotheses were confirmed.

In Paper II, the mean total disability score (SE) was 30 (0.5), with the six domain scores ranging from 11.9 to 44.7. The following variables were found to predict higher total disability score: neurological diseases, multimorbidity, low education, impaired physical fitness, pain, and symptoms of depression. For all disability domains of WHODAS 2.0, a lower Hospital Anxiety and Depression Scale (HADS) score predicted lower disability score.

Paper III showed that SOC score was associated with reduced disability scores in the following domains of WHODAS 2.0: Cognition, Getting along, and Participation. Two structural models were compared for variables with direction of the association from SOC to HRQoL and disability or with disability as a mediator. Better SOC led to reduced disability which led to better HRQoL. The mental component of HRQoL had better model fit than the physical component. For both models, circulatory diseases reached a good fit whereas less good fit was reported for musculoskeletal diseases.

### Conclusions and implications

This study supports the use of WHODAS 2.0 as an instrument to investigate disability among rehabilitation patients. Our findings indicate that the instrument has limitations in detecting short-term changes after discharge from a rehabilitation centre.

A moderate total disability score was found among patients entering a rehabilitation centre. The fairly high score in the disability domain of Participation, in addition to the domain Life Activities, should be considered when developing rehabilitation strategies.

Disability may be reduced by targeting its predictors. Our results indicate that higher SOC decreases the score in disability domains with mental components. The role of SOC in relation to disability and HRQoL might vary between diagnostic groups. In rehabilitation, SOC could be a target for enhancing mental components of HRQoL, especially among patients with circulatory diseases.

# List of publications

#### Paper I

Moen VP, Drageset J, Eide GE, Klokkerud M, Gjesdal S. Validation of the World Health Organization Schedule 2.0 in specialized somatic setting. Quality of Life Research. 2017;26(2):505-14

### Paper II

Moen VP, Drageset J, Eide GE, Gjesdal S. Dimensions and predictors of disability - A baseline study of patients entering somatic rehabilitation in secondary care. PLoS One. 2018; 3(3): e0193761.

#### Paper III

Moen VP, Eide GE, Drageset J, Gjesdal S. Sense of Coherence, disability, and health-related quality of life: a cross-sectional study of rehabilitation patients in Norway. Archives of Physical Medicine and Rehabilitation. Accepted 3 June 2018.

"The published papers (Papers I, II and III) are open access articles distributed under the terms of the Creative Commons Attribution License."

# **Abbreviations**

CFA Confirmatory factor analysis

CI 95 % confidence interval

COSMIN COnsensus-based standards for the Selection of health status

Measurement INstruments

EQ-5D-5L European Quality of Life Scale 5 Dimensions 5 Levels Scale

HADS Hospital Anxiety and Depression Scale

HRQoL Health-related quality of life

ICF International Classification of Functioning, Disability and Health

ICC Intraclass correlation coefficient

MI Multiple imputation

PROs Patient-reported outcomes

SF-36 Medical Outcomes Study Questionnaire Short Form 36 Version 1

SD Standard deviation

SE Standard error

SEM Standard error of measurement

SOC Sense of coherence

SOC-13 Sense of Coherence 13-item questionnaire

WHO World Health Organization

WHODAS 2.0 World Health Organization Disability Assessment Schedule

version 2.0

### 1. INTRODUCTION

The World Health Organization (WHO) estimates that 15% of the world's population has some form of disability [1]. Rehabilitation which is the main health strategy targeting disability [2], has high priority in Norwegian health policy [3, 4]. While 1.814.573 patients with at least one stay were treated in a somatic hospital in 2013 [5], 55.207 patients received rehabilitation in secondary care [6]. The cost of rehabilitation has been estimated to be approximately 1.5–2.0 billion Norwegian kroner or 0.20–0.25 billion euros [7].

Despite the costs in the billions and other expenses related to the consequences of a lack of rehabilitation, such as labour and social costs, the rehabilitation field in Norway has had low status with weak recruiting and limited research activity [7, 8]. Consequently, the Centre for Habilitation and Rehabilitation was established in 2007of the Western Norway Health Authority, as part of a long-term strategic initiative with a focus on rehabilitation. A main task of this centre is to promote and conduct research in rehabilitation with the aim to strengthen the scientific basis.

Rehabilitation largely takes place at rehabilitation centres in secondary health care [6]. Although research at these centres occurs in the Western Norway Health Region, it is to a limited extent, and specific diagnostic groups are often investigated [9, 10]. In Norway, age, sex and the health condition at referral of patients entering rehabilitation centres in secondary care are systematically reported. However, systematic investigation of these patients on a large scale has not been conducted in the country; consequently, there is sparse knowledge of their health characteristics. A challenge in disability assessment is that comparability of data is hampered by differences in definitions and classifications of the main outcome measures, measurement methods, and data sources [1].

Rehabilitation aims to optimise functioning, and rehabilitation patients usually have chronic and incurable health conditions with disability as the common health variable. Functioning is defined as the third health indicator in the health system and the key

indicator for rehabilitation [11]. Along with mortality and morbidity data, reliable and comprehensive data on functioning and other rehabilitation outcomes is necessary for research that may strengthen rehabilitation in the health system [12]. Together with the complexities involved in all the components and predictors, gaining an understanding of functioning and disability among patients in rehabilitation is a major challenge for clinicians, researchers, and policymakers [13].

Data on disability and health status among rehabilitation patients allow governments and stakeholders to document living conditions and life situations among people with disabilities [14], and to gain understanding of factors associated with disability and other important health variables. This is necessary when developing strategies needed to improve the health status of people with disabilities [15]. Assessment of disability and functioning together with diagnoses can predict service needs, level of care, outcome of the condition, work performance and social integration [16].

In addition to mobility, sensory, or cognitive impairments, rehabilitation patients experience limitations in daily activities and participation restrictions. Instruments that solely assess basic activities of daily living are most often used, and measures of participation in society (e.g. an individual's experience of participation restrictions) is less developed [17, 18]. Consequently, the distribution and associated factors of this important disability domain among rehabilitation is sparse.

Finally, to gain better control over their life situations, strengthening the patients' resources which promotes successful coping and health, is emphasized in rehabilitation by the Norwegian national authorities [3, 19]. To our knowledge, and for clinical implications, the relationships between sense of coherence (SOC) and disability and health-related quality of life (HRQoL) among rehabilitation patients with various health conditions have not been investigated.

### 1.1 Rehabilitation

'Rehabilitation is to be a key word in medicine', predicted William Mayo, one of the founders of the Mayo Clinic, in 1925 [20]. Almost 100 years later, rehabilitation is recognised to be the principle health strategy for the 21st century [21]. Moreover, rehabilitation has been proposed to be the third element in medicine, after preventive and curative medicine [22].

The noun rehabilitation comes from the Latin prefix re-, meaning 'again' and habitare, meaning 'make fit'. The Romans built thermal baths for wounded soldiers who needed to recuperate. Rehabilitation is defined as 'a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments' [1], and is 'instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and participate in education, the labour market and civic life' [1].

Although rehabilitation has a long tradition in medicine, rehabilitation as a systematic and methodologic service is relatively new. In the Nordic countries, institutions for people with disabilities were established in the 19th century [22]. In the interwar period and after the Second World War, rehabilitation as a service received much attention because the need for labour was high and soldiers and other people with injuries were considered a labour reserve [22]. The Universal Declaration of Human Rights signed in 1948, was an essential step towards establishing equal rights for all people to participate in society, which resulted in an increasing need for rehabilitation. The establishment of institutions, development of social medical expertise, and systematic interdisciplinary teamwork are important features that have developed since the 1950s [23].

Rehabilitation was described as a main health strategy in the Declaration of Alma-Ata in 1978, with functioning as the main outcome of interest [2]. Rehabilitation is not a single treatment but should be considered a response to disability, targeting patients with different health conditions. The involvement of the patient as an active participant

in the process is emphasized because the goal is based on the patient's needs and life situation. Rehabilitation does not focus on treating a specific disease but rather on resolving one or more particular problems. The integration of medical and social models, resulting in a holistic perspective, is characteristic of rehabilitation [23]. This means targeting body functions and body structures as well as various social aspects of life, such as occupation and education, among others. Rehabilitation involves many actors and embraces many disciplines: medicine, psychology, social work, employment, sociology, jurisprudence, and technology [22]. This diversity enables many perspectives and also challenges how rehabilitation services are organised.

# 1.1.1 Rehabilitation in Norway – the role of the private rehabilitation centres in secondary care

Rehabilitation is provided in a wide range of settings in Norway, including hospitals, rehabilitation wards, rehabilitation centres, nursing homes, and multiprofessional practices. In Norway, rehabilitation is provided in primary care and secondary care. The need for specialised competence is decisive with respect to whether rehabilitation takes place in secondary or primary care [3]. The potential for rehabilitation indicates a prognostic evaluation of the levels of functioning an individual is capable of reaching under certain circumstances [24].

The task in primary care is to provide health services near the patient's place of residence [25]. Primary care has competence related to opportunities and limitations in the local community. As a rule, health services for large patient groups are developed and offered in primary care [3]. Rehabilitation of people who need long-term and coordinated follow-up, and cooperation between public bodies, should take place in primary care [25].

In secondary care, which in Norway is also referred to as specialised health care, rehabilitation is often combined with surgery and other medical treatment. Although the primary purpose of hospitalisation is not rehabilitation, rehabilitation is closely related to medical treatment. In 2006, private rehabilitation centres became a part of

secondary care. These centres provide rehabilitation services according to requirement specifications and in line with national recommendations.

Secondary care is divided into four health regions in Norway (Regional Health Authorities): South-Eastern, Western, Central, and Northern. Each health region decides the scale, design, and quality of rehabilitation services. Consequently, there are relatively large variations in the number of inpatient and outpatient registrations in rehabilitation, both in hospitals and at rehabilitation centres. Whereas the Central health region has the greatest use of rehabilitation services in hospitals, the Northern region has the most people receiving inpatient rehabilitation in centres [6]. The Western region has the least use of rehabilitation services in secondary care. Whereas rehabilitation for neurological and circulatory diseases is predominant in hospitals, the proportion is highest for musculoskeletal diseases at rehabilitation centres [6].

Patients are referred to rehabilitation centres directly from home or after hospitalisation. Although patients from hospitals are referred directly, those from primary care (from home) are assessed through referrals at an assessment unit in each region. In the Western Health Region, this unit is known as the Regional Vurderingseining for Rehabilitering. Each year approximately 4000 referrals are assessed at this unit and 65% of patients are accepted for rehabilitation. Through June 2017, patients were assigned to a rehabilitation centre in the same health region, as a rule. Since June 2017, patients can choose freely between all rehabilitation centres in Norway that offer services matching their health condition.

# 1.2 Patient reported outcomes and their importance in surveys

In health science, health variables are obtained through clinical studies, intervention studies and surveys. Diagnoses of many diseases are based on changes in biological and physiological variables, i.e. observable variables such as morphological changes in tissues and pathophysiological processes. These measurements are usually taken by clinicians using laboratory and imaging tests.

In contrast to these measurements, which are considered objective (i.e. having no ability to influence the measurement), subjective measurements capture the impact of health or disease on individuals in their environment. 'Any reports or information coming directly from the patient, without interpretation of the patients' responses by a clinician or anyone else', are defined as patient-reported outcomes (PROs) [26].

The inclusion of PROs enables us to measure unobservable variables and constructs with multidimensional aspects, such as perceived health. In rehabilitation patients, individuals' living conditions and their experience of disability and health can only be obtained from the individuals concerned [27]. PROs complement clinical data, biomarkers, and degree of morbidity and provide a holistic interpretation of the health variables under investigation [28]. As for chronic conditions, survival is not the most relevant outcome because these conditions mostly do not affect mortality.

PROs can be characterised as one of five principal types [29]: generic, disease or population specific, dimension specific, individualised, and utility. Whereas generic instruments are meant for general use and for healthy populations, disease-specific instruments focus on the issues of particular concern for specific diseases or groups of diseases. Generic instruments cover the main dimensions of the variable under investigation, which is an advantage when comparing results across different groups and with general population norm scores. Disease-specific instruments are more sensitive for discovering small but clinically significant changes. Domain-specific instruments assess particular issues in greater depth rather than covering many dimensions or aspects of the variable under investigation, such as anxiety, depression, and pain. Individualised measures are based on the respondents' most important aspects of their own life, allowing inclusion and weighting of these aspects. Utility measures have been developed for economic evaluation.

In addition to the use of PROs in clinical settings, their use in health surveys is of great interest when monitoring health on a large scale, such as population surveys, and within development and evaluation of health care service and quality improvement [28, 30]. Health surveys are a common methodology in health and behavioural science

for collecting information that is not readily available from official registers and medical records. Self-administered questionnaires are a common tool in population-based surveys; medical outcome studies pioneered the use of this methodology [28]. An advantage to using this method is the ease of administration, for reaching many people at the same time. Using self-administered questionnaires facilitates standardization to avoid possible systematic differences in interviewing technique. Furthermore, for researchers, this method requires few resources when collecting data as patients complete the questionnaire themselves.

# 1.3 Measurement properties of outcome measures and validation of instruments

To conduct empirical research, investigators need reliable and accurate measures of the variables of interest, i.e. to capture numerical representations (data) of the phenomena of interest and test relationships among them. Whereas observable variables are measured directly, measuring unobservable variables requires another approach. To measure these variables, or constructs as they are known, researchers capture manifestations that are directly observable and represent the underlying construct. To operationalise this, multi-item measurement instruments have been developed. As the method measures observable characteristics related to nonobservable constructs, testing is required to evaluate the accuracy of manifestations of the construct. Poor quality of a measurement instrument implies imprecise or biased results, which may lead to false conclusions. Consequently, measurement properties must be investigated to assess the quality of an instrument by considering its qualitative attributes, i.e. the construct that is being measured, the purpose and target population, its format, interpretability, and ease of use [31].

There is a lack of consensus about terminology and definitions of measurement properties across the different fields that contribute to existing health measurement. Therefore, an international multidisciplinary team consisting of researchers with expertise in epidemiology, psychometrics, statistics, and health care formed COSMIN (COnsensus-based Standards for the selection of health Measurement Instruments).

This group performed a Delphi study and in 2010, they published their consensus on terminology, definitions, and taxonomy of the relationships among measurement properties of health-related patient outcome measures [32]. Table 1 presents COSMIN definitions of domains, measurement properties, and aspects of measurement properties [32].

**Table 1** COSMIN definitions of domains, measurement properties, and aspects of measurement properties (Reprinted with permission from Elsevier) [32]

Term			
Domain	Measurement property	Aspect of a measurement property	Definition
Domain Reliability Reliability (extended definition)	Internal consistency Reliability	projecty	The degree to which the measurement is free from measurement error The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: for example, using different sets of items from the same HR-PROs (internal consistency), over time (test—retest) by different persons on the same occasion (interrater) or by the same persons (i.e., raters or responders) on different occasions (intrarater) The degree of the interrelatedness among the items The proportion of the total variance in the measurements which is because of "true" differences among patients
	Measurement error		The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
Validity	Content validity		The degree to which an HR-PRO instrument measures the construct(s) it purports to measure  The degree to which the content of an HR-PRO instrument is an
	contain running	Face validity	adequate reflection of the construct to be measured  The degree to which (the items of) an HR-PRO instrument indeed looks as though they are an adequate reflection of the construct to be measured
	Construct validity		The degree to which the scores of an HR-PRO instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the HR-PRO instrument validly measures the construct to be measured
		Structural validity	The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured
		Hypotheses testing Cross-cultural validity	Idem construct validity  The degree to which the performance of the items on a translated or culturally adapted HR-PRO instrument are an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
	Criterion validity		The degree to which the scores of an HR-PRO instrument are an adequate reflection of a "gold standard"
Responsiveness			The ability of an HR-PRO instrument to detect change over time in the construct to be measured
Interpretability <sup>b</sup>	Responsiveness		Idem responsiveness  The degree to which one can assign qualitative meaning—that is, clinical or commonly understood connotations—to an instrument's quantitative scores or change in scores.

Abbreviations: HR-PROs, health-related patient-reported outcomes; CTT, classical test theory.

<sup>&</sup>lt;sup>a</sup> The word "true" must be seen in the context of the CTT, which states that any observation is composed of two components—a true score and error associated with the observation. "True" is the average score that would be obtained if the scale were given an infinite number of times. It refers only to the consistency of the score and not to its accuracy (ref Streiner & Norman [12]).

b Interpretability is not considered a measurement property but an important characteristic of a measurement instrument.

### 1.4 DISABILITY

### 1.4.1 Historical background – from a medical model to the International Classification of Functioning, Disability and Health

Disability has been regarded as an individual trait, the result of a cause rooted in body impairment. Throughout history, several people have been given nicknames because of their body impairments. From the age of the Vikings, Erling Ormsson got his nickname 'Skakke' when his neck became crooked after his throat was cut in a battle with the Arabs. Ivar the Boneless, another well-known Viking, was described as lacking bones. Although the origin of his nickname is uncertain, it may be explained by the genetic condition osteogenesis imperfecta. The disability model which addresses impairments is termed the medical model or the biomedical model. In this model, the consequences of impairments that result in difficulties or hindrances to daily activities and social participation are emphasized. Conceptualised in the medical field, this model aims to define the criteria of eligibility for services, aid, and other assistance. This model is likely recognised as the main model in colloquial language because disability is considered a health issue of interest to medical professionals. This understanding of disability has led to the institutional model of how disability should be treated. The general objective of the medical model is to focus solely on the individual's deficiencies.

From the 1960s, those involved in the social sciences became interested in the concept of disability, and the environment became recognised as an important variable when assessing the inability to perform certain roles and tasks [24]. The sociologist Saad Nagi, who is recognised in the literature as a pioneer in the work towards developing a conceptual framework of disability, refers in his research to how people who are incapacitated are defined by others, stating that 'disability is the expression of a physical or a mental limitation in a social context' [33]. He argued that factors other than impairments alone contribute to the dimensions and severity of disability. The definition of and reactions to the situation from both the individual and others are essential. Nagi treats 'others' as people who are significant in the lives of the person

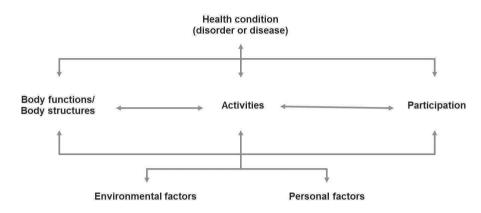
(family, friends, employers, organizations, service providers, and so on). Additionally, environmental characteristics, including physical and sociocultural barriers, contribute to the various aspects of disability.

In 1972, the Union of the Physically Impaired Against Segregation (UPIAS) was founded in the United Kingdom [34]. The aim of UPIAS was to change the perception of disability from a fault in the individual to a shortcoming of society. UPIAS is considered an important organization in the development of a social model of disability. Additionally, disability movements in Sweden have actively contributed to a new perspective on disability [35]. Whereas the medical model takes the society and the environment for granted, the model that is recognised as a social model considers the construction of the society to be essential, rendering humans a product of the society's norms and values [36]; hence, disability may be considered a social construct [17]. UPIAS comprises academics with disabilities and defines disability as 'the disadvantage or restriction of activity caused by contemporary organization which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities' [37]. Additionally, UPIAS also rejects the thoughts and opinions of 'experts' who prescribe how people with disabilities should live their lives. In the social model, treatment of disabilities is secondary. Regardless of medical advances, some people will always live with disabilities. Barriers arise as a result of the design of environments that result in exclusion. Such a design does not consider the diversity and variety among human beings, and it ignores the objective of facilitation for all in an equal manner and not only for the majority or for normality. Indeed, the term 'people with disabilities' was changed to 'disabled people' to emphasize causality.

The biomedical and social models are often considered two extremes where the social model was developed as a reaction against the focus on the individual. Whereas the medical model blames the individual, a social perspective faults the society and its structures and systems.

However, people experience situations in which the demands are greater than their abilities. This third model, which points to a gap between the individual's capacity and the demands of society, is termed the Nordic model [14]. This model considers that there is a relationship between the person and the environment or situation, that is, practical problems arise from inconsistency between an individual's functional ability and the functional requirements of the environment. In Norway, this relationship was used as the definition of disability in a white paper concerning disabled people in the 1990s [14]. A subsequent white paper on people with disabilities clarified that 'environment' not only involves the physical environment but also a number of societal conditions [38].

A decade after Nagi proposed his model, the biopsychosocial model of health was published, arguing for the evaluation of all factors that contribute to illness and patient hood and not only biological factors [39]. In the same decade as the WHO recognised that the International Classification of Diseases (ICD) was unsuitable for chronic conditions, the WHO consequently aimed to improve the classification of rheumatism by describing the consequences of the disease. However, the aim of their work became to develop a classification system in which consequences of disease, injuries, or disorders were addressed. Thus, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was issued by the WHO in 1980 [40]. However, this model was criticised for conceiving disability and handicap as being caused by impairment and therefore requiring appropriate medical intervention and treatment [41]. Additionally, the ICIDH failed to acknowledge the presence of social barriers. As a response, the WHO released the ICIDH version 2 which was later revised and released as the International Classification of Functioning, Disability and Health (ICF) in 2001 [42]. The ICF emphasizes a relational understanding of disability as a complex relationship between an individual's health condition and the contextual factors, including personal and environmental factors (Figure 1). The result of this complex relationship is expressed through impairments, limitations to activity, and restrictions to participation.



**Figure 1** The ICF Model: Interaction between ICF components [42]

### 1.4.2 Measuring disability

Together with mortality and morbidity, disability provides a complete set of indicators for monitoring the performance of health strategies in health systems [11]. However, there is no consensus on an internationally standardised measure of disability, and operational measurement varies considerably. The operational definitions chosen are likely to affect the research outcomes [43]. The possibility of comparing results across studies is therefore limited. In Norway, a single survey using several disability measurements reported disability rates in Norway from 10% to 28% [44]. Furthermore, that study showed a low level of agreement across various definitions. The different operational definitions resulted in different people being classified as disabled or not disabled. This is in line with a French study which emphasized the sensitivity and feasibility of screening methods [27]. Additionally, the perception of what constitutes a limitation may not be the same in different populations. Factors determining self-attribution of a disability and its social recognition are not the same before and after 60 years of age [27]. In one report, among people who received official recognition of their disability, 10% (mostly men and younger people) did not attribute a disability to themselves or report any restriction of activity [27]. Also in that study, people aged > 60 years reported activity limitations but did not acknowledge or seek official recognition of a disability.

There are five methods for measuring disability [35]: subjective, administrative, functional, relational, and social assessment. The first three are the most frequently used and are described in this chapter whereas the latter two methods point towards the relationship between the individual and their surroundings and barriers, respectively, which are difficult to measure [35]. Subjective assessment is conducted by asking people if they consider themselves to be disabled or to have a disability. Statistics Norway conducts population surveys known as 'Levekårsundersøkelsen' [45]. Administrative assessment often uses data from public registers. In this method, only people who fulfil specific criteria, e.g. labour and health measures, are counted. Functional assessment is the method most often used in medical research, in which functional tasks are assessed and the difficulties in performing tasks are rated. One of the first definitions of functional assessment was proposed by Powell Lawton in 1971 as 'any systematic attempt to objectively measure the functional level in a variety of domains' [46]. At that time, functional assessment was nearly considered unmeasurable [47].

Most disability measurements use operationalisation that is in keeping with the concept of impairment [43]. Basic activities of daily living are often included. Items concerning participation in society are seldom included in the instruments [18] because most instruments were developed during a period when disability was conceptualised according to the medical model. Publication of the ICF in 2001 emphasized the importance of participation in society as an important domain when assessing disability. As a conceptual framework, the ICF is useful because it clarifies aspects and outcome measures in rehabilitation. However, instruments developed before publication of the ICF are still used.

# 1.4.3 The World Health Organization Disability Assessment Schedule version 2.0

WHODAS 2.0 is considered the current leading measure of disability worldwide [48]. It is a generic assessment instrument developed by the WHO to provide a standardised method to measure disability across cultures. The ICF defines disability as 'a decrement in each functioning domain' [42]. As the ICF is impractical for assessing

and measuring disability in daily practice, WHODAS was developed to address this need [49].

WHODAS 2.0 was constructed through a cross-cultural study with the involvement of 19 countries around the world. An extensive review of existing instruments was performed to explore and select items before field testing. Members of the general population in good health and people with physical as well as mental and emotional disorders were tested; people with problems related to alcohol and drug use were also included. WHODAS 2.0 is designed to assess the activity limitations and participation restrictions experienced by an individual, irrespective of medical diagnosis. Six disability domains are recognised as the most common and elementary:

Communication and understanding (abbreviated Cognition), Mobility, Self-care, Getting along with others (abbreviated Getting along), Life activities, and Participation in society (abbreviated Participation).

The history of the instrument spans from 1988 when the WHO Psychiatric Disability Assessment Schedule was developed, which was designed to assess the extent of disability associated with a psychiatric condition. In June 1999, that instrument was further developed to disseminate a beta version of its generic assessment instrument, the WHO Disability Assessment Schedule II (WHODAS II), and address the issue of effective assessment of disability [48]. A systematic review examining use of the WHODAS 2.0 in 2017 identified 810 studies from 94 countries published between 1999 and 2015 [48]. This extensive use of the instrument reveals its great importance for collecting data on disability, and the proportion of studies published on nonpsychiatric conditions shows that the instrument extends to all life sciences and is not only limited to psychiatry [48].

Self-reporting versions of the instrument exist; there are 12-item, 36-item, and 12+24-item versions. WHODAS 2.0 has been translated into numerous languages and has been validated for many diagnoses/health conditions [48, 50].

# 1.5 Health and health-related quality of life and its measurement

'Health is silent' is a Swedish expression, after a poem by Erik Gustaf Geijer, meaning that when we are healthy and feeling good, we usually do not notice it. Health is a concept to which every individual has a relationship; however, there is little consensus on the definition of health. Health has been defined as being in a state of harmony with others and having a cosmic understanding of balance. Another definition is a biomedical understanding, namely, having no dysfunction in body structures or body functions [51-53]. Moreover, health has been described as the critical outcome of a continuous individual struggle, or as a capacity to adapt to contextual factors and function normally in the community most of the time [51-53].

Definitions of health may be classified according to contrasting principles [54]. Whereas positive principles characterise health as a surplus to everyday requirements, the absence of disease is a negative principle. Subjective theories address the personal experience of health, and objective theories quantify the concept. Reductionist theories are based on disease whereas holistic theories embrace the whole of human life. In maximalist theories, health is close to happiness whereas minimalistic theories define health as the absence of something undesirable, i.e. pain, disability, and so on. The nominalist and existentialist principles respectively define health as something absolute and something relative which varies with time and place.

In 1946, the WHO defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' [55]. This definition would be classified within the holistic and the maximalist principles. However, the definition lacks operationalisation of both how to measure it and how it is produced [53].

From the various definitions of health, as a multidimensional concept, five distinct dimensions have been identified [56]: physical health, mental health, everyday functioning in social and in role activities, and general perceptions of well-being. These five dimensions, which are conceptually distinct and universal, are

recommended as a minimum standard for health measures that claim to be comprehensive [56].

It has been argued that there are two structurally different meanings of health [57]. One meaning is curing as an intervention to stay healthy; a more comprehensive concept includes quality of life (QoL). Well-being in the WHO's definition may reflect the QoL aspect. QoL is defined as 'the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns' [58]. Whereas QoL incorporates all factors that have an impact on an individual's life, HRQoL was introduced to assess only those factors that are a part of an individual's health [59]. HRQoL as an endpoint has gained interest the last five decades in medical care and clinical trials [60]. Subjective costs of medical treatment, i.e. adverse and side effects compared to longer longevity, may explain this development to some extent. To provide better rehabilitation for the individuals, the subjective perspective of patients is important.

Maximizing the health component of QoL is recognised as the goal of health care systems [1, 56, 61] in providing comprehensive evaluation that encompasses all important aspects. HRQoL incorporates, at a minimum, physical, psychological, and social functioning [26] and may also measure impairments, symptoms, or disability. HRQoL generally involves the patients' own perception [60, 62]. Clinical data, such as measures of biological and physiological function, tissue diagnoses, and patient-reported symptoms, are only occasionally included in conceptualizations of HRQoL [62]. HRQoL is thus subjective and multidimensional. This is in line with the WHO's definition of health addressing physical, mental and social aspects of life.

The purpose of HRQoL measurement is to quantify, in a valid and reproducible way, the degree to which a medical condition or its treatment impacts an individual's life [61]. Hence, HRQoL is an important indicator, used along with traditional measures (e.g. mortality and morbidity) to capture the burden of the health condition. Measurements of HRQoL can be used to assess changes over time, e.g. in surveys and clinical trials. The measurements can be used when comparing patients with different

conditions (e.g. the relative impact of musculoskeletal versus circulatory disease) or in clinical trials or comparative effectiveness research where patients receive different treatments [3].

### 1.6 Sense of coherence

As mentioned in the previous section, health has also been proposed as reflecting the individual's capacity to respond to challenges.

'Health is a person's psychological capacity to act or respond appropriately (in a way that is supportive of the person's goals, projects and aspiration) in a wide variety of situations.' Whitbeck 1981 [63]

Whereas disability is defined by the ICF as a decrement in a functional domain, HRQoL is often measured according to negative aspects of health, reflecting physical/psychological morbidity and aetiology [64]. Contrary to pathogenesis, a salutogenic framework focuses attention of the origins of health.

Aaron Antonovsky, an American-born medical sociologist, studied adaptation to climacterium among women of different ethnic groups in Israel [65]. In his data, he found that two-thirds of participants who had survived Nazi concentration camps still felt troubled concerning their emotional health. However, Antonovsky was especially interested in the nearly one-third of participants who reported positive emotional health despite their experiences in the camps. His interest on psychological health resources resulted in his salutogenic approach which attempts to explain why some people remain healthy when facing severe hardship when others do not.

Life events called stressors are an inevitable part of human life as the human environment often causes strain [65]. Facing a stressor triggers an excited state in an individual, one which needs to be dealt with. The outcome, negative (pathological), neutral, or positive (health promoting), depends on whether this tension is successfully handled. Dealing with stressors adequately requires coping resources, and Antonovsky used the term general resistance resources (GRR), which concern all factors that

provide protection against a wide range of stressors defined as 'every characterization of a person, group, or environment that promotes effective management of tension' [65] Examples of GRR are money, ego identity, cultural stability, social support, and immunological features. However, Antonovsky sought a construct in which shared components of GRR could be characterised. This construct was called sense of coherence (SOC). SOC is an orientation to life and is defined as 'the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's environment is predictable and that things will work out as well as can reasonably be expected' [65].

SOC consists of three main components: comprehensibility, manageability, and meaningfulness. Comprehensibility concerns whether an event is understood, manageability concerns whether a person believes that resources to cope are available, and meaningfulness addresses whether the person believes that the event is worth an investment of time and resources.

A person with better SOC views and responds differently to a stressor than a person with weaker SOC. A person with a better SOC is presumed to define a stimulus as a nonstressor and to automatically assume that they will be able to meet the demand. Furthermore, this person may experience a greater degree of meaningfulness in life events (stressors) compared with a person who has weaker SOC, which in turn may result in better regulated emotions. Regulated emotions, which are a part of coping [66], are consistent with the perception that problems are understandable whereas diffuse emotions may result in defence mechanisms. Early experiences of success with managing situations and stress factors imply a realistic attitude about how to face stressors later in life. The ability to cognitively and emotionally structure the perception of a stress factor and accept that one has to deal with it contributes to successful management of the stressor [65]. Better SOC means choosing the strategy that is best for handling the stressor and selecting the most appropriate resources available. People with the opposite, weaker SOC, may capitulate in the face of attempting to deal with the stressor. However, Antonovsky did not argue for a specific cut-off between good or weak SOC.

The conceptual framework of SOC shares similarities with other coping theories such as Bandura's theory of self-efficacy and locus of control theory with cognitive and motivational aspects. However, instead of exhibiting a fixed behaviour in a given situation or developing ways to control events [67], SOC is considered a flexible life orientation to problem solving and better SOC promotes successful coping [68]. SOC has been shown to be positively associated with self-efficacy and locus of control and negatively associated with learned helplessness [65].

Development of SOC begins in early childhood and ends at around the age of 30 [65]. It is assumed to be stable thereafter, although this supposition has received criticism. A Swedish longitudinal population study showed changes in SOC [69]; participants scoring lowest on SOC initially, or those with a disease at enrolment, had the largest decrease in SOC score after 5 years. Men seemed to be less affected than women when experiencing a loss of perceived good health and substantial social changes [69]. However, the same study showed that SOC was only stable in participants with initially high levels of SOC [69]. Other studies have shown that SOC both increases and decreases with increasing age [70, 71].

The evidence of association between SOC scores and health is undebatable. According to a systematic review of 458 scientific publications and 13 doctoral theses [72], SOC has a major, moderating, or mediating role in the explanation of health. Furthermore, it appears to be able to predict health [73]. Mental components of health and SOC are strongly associated; the relationship between physical components of health and SOC is more unclear.

# 2. AIMS

The overall aim of this thesis was to investigate health status, with the main focus on disability among patients entering rehabilitation centres in secondary care. A prerequisite for accomplishing this was to clarify conceptual models of disability or how disability could be measured, among others. Additionally, to gain understanding of how disability can be influenced and its association with other important outcomes, to increase the clinical relevance of the study, the relation of disability to SOC and HRQoL was investigated.

### The specific objectives were:

- 1. To evaluate the measurement properties of the Norwegian version of WHODAS 2.0 in patients entering rehabilitation centres in secondary care, with respect to feasibility, reliability, validity, and responsiveness (Paper I)
- 2. To investigate disability among rehabilitation patients and its predictors (Paper II)
- 3. To investigate the role of SOC and its relation to disability and HRQoL among rehabilitation patients (Paper III)

# 3. METHODS

# 3.1 Design

This study is based on data from a prospective cohort study investigating patients in the Western Norway Health Region before and after a stay at a rehabilitation centre. This study was financially supported by the Centre for Habilitation and Rehabilitation in the Western Norway Health Region.

All papers used baseline data which was collected during the first half of 2015. PROs were collected using a questionnaire. Instruments that are widely known and have been tested in Norwegian settings and in similar populations were used, in addition to other items concerning health and rehabilitation. Additionally, individual sociodemographic data from public registers were obtained from Statistics Norway.

# 3.2 Study participants and recruitment

Inclusion of patients was conducted from two referral paths: 1) at rehabilitation centres, or 2) invitation by mail from a waiting list held by the assessment unit, i.e. Regional Vurderingseining for Rehabilitering. One research assistant at each rehabilitation centre in the Western Norway Health Region (Red Cross Haugland, Ravneberghaugen, Åstveit, LHL Krokeide, LHL Nærland, and Rehabilitation West) was appointed to recruit patients and to administrate data collection. These six research assistants received verbal and written information and instructions about the recruitment and administration processes. The research assistants provided oral and written information about the study to patients and ensured that their informed written consent was obtained. Personal and phone contact with research assistants was maintained continuously throughout the recruitment period. These contacts dealt with practical information and involved discussions concerning how to increase the response rate. For patients recruited at rehabilitation centres, the questionnaire was completed within the first 2 days after their admittance.

All referrals of patients from primary care for admission to a Norwegian rehabilitation centre in secondary care are assessed. In the Western Norway Health Region, assessment is performed in the following order at Regional Vurderingseining for Rehabilitering. First, the referral is registered with the date, main diagnoses (ICD-10 chapter), other diagnoses, and preferred rehabilitation centre. Second, the referral is assessed by a medical doctor affiliated with Rehabiliteringsklinikken at Haukeland University Hospital. The time from receipt of the referral to a decision about whether the patient is entitled to rehabilitation in secondary care is a maximum of 30 working days (in November 2016, this was reduced to 10 working days). Third, an acceptance letter is sent to the patient, the rehabilitation centre, and the person who referred the patient, usually a general practitioner.

For this study, shortly after acceptance letters were sent, patients from the waiting list were mailed information about the survey, along with the questionnaire and a prepaid envelope. One reminder was sent to nonrespondents one month after the initial invitation. In cases where the invitation was returned because of a wrong address, the population register was used to retrieve any new address.

Patients were eligible if they were over 18 years of age. Patients were excluded if they were referred for lifestyle changes owing to morbid obesity as these patients have different referrals paths, i.e. they are referred from each hospital. Additionally, people who had a follow-up stay were excluded because rehabilitation had already been initiated.

Information about the sex and age of nonrespondents was noted.

# 3.3 Methods and measurements

# 3.3.1 Methods for all Papers

The survey was planned and the questionnaire was developed in 2014 mainly by Sturla Gjesdal, Øystein Hetlevik, Merethe Hustoft and Vegard Pihl Moen with Geir Egil Eide and Jorunn Drageset as important planning fellows.

In the planning process, topics concerning comparability, efficiency, nonredundancy, validity, reliability, and feasibility were discussed. The survey was structured using the following sections of questions: date, sex, main diagnosis, additional diagnoses, physical fitness, physical activity, smoking, health care utilization, patients' perception of continuity of care service by the Nijmegen Continuity Questionnaire, disability by WHODAS 2.0, HRQoL by the Medical Outcomes Study Questionnaire Short Form 36 Version 1 (SF-36), symptoms of anxiety and depression by the Hospital Anxiety and Depression Scale (HADS), coping by the Sense of Coherence 13-item questionnaire (SOC-13), and health status by the European Quality of Life Five Dimensions Five Levels Scale (EQ-5D-5L).

The questionnaire was pilot tested to uncover any weaknesses and uncertainties and to measure the completion time. Three colleagues, all women between age 41 and 46 years who had no knowledge of the survey content, completed the questionnaire in 21, 22, and 24 minutes. Additionally, 33 rehabilitation patients (18 women and 15 men, age 40–86 years) from four rehabilitation centres completed the questionnaire in November and December 2014. Completion times ranged from 21 to 90 minutes, with mean time 36.6 minutes and median time 35 minutes.

All questionnaires were manually plotted by the doctoral candidate. Ninety-five randomly selected questionnaires were plotted twice to check for plot agreement, with 16,055 items in total. The overall disagreement was 0.33%. For the internationally validated instruments used in this thesis, the proportions of error were: WHODAS 2.0, 0.52%; SF-36, 0.08%; HADS, 0.15%; SOC-13, 0.42%; and EQ-5D, 0.21%.

After the inclusion period, all rehabilitation centres were contacted to ensure that patients were not registered twice, once from the waiting list and once from the centres.

In autumn 2016, PROs were linked to individual public register data on educational attainment, municipality of residence, and marital status. Consequently, register data were not accessible when Paper 1 was published.

#### 3.3.2 Methods in Paper I

After completion of WHODAS 2.0, a sample from the waiting list was randomly selected, to complete the instrument a second time and explore the reproducibility. The criteria for inclusion in this analysis were completing the WHODAS 2.0 within 15 days or less and reporting no change in health status after the first completion.

A sample of the patients included at rehabilitation centres was randomly selected to investigate the short-term responsiveness of WHODAS 2.0. The criterion for inclusion in this analysis was completion of the WHODAS 2.0 within 3 months, with a minimum 4 weeks, after discharge from the rehabilitation centre.

## 3.3.3 Methods in Papers II and III

Survey questions concerning physical fitness (Paper II) followed the same format as in the Nord-Trøndelag Health Study (HUNT-3) [74]. Multimorbidity was defined as the presence of more than one self-reported chronic condition in the same individual and was evaluated based on the referral diagnosis and a list of predefined conditions. For a fair evaluation of multimorbidity, data on at least 12 relevant chronic diseases are needed [75]. Additional diagnoses were the same as those used in HUNT-3 because this population survey included a wide range of ages. The additional diagnoses included heart attack, angina pectoris, heart failure, other heart disease, stroke/cerebral haemorrhage, kidney disease, asthma, chronic bronchitis/emphysema/chronic obstructive pulmonary disease, diabetes, cancer, epilepsy, rheumatoid arthritis, Bechterew's disease, sarcoidosis, osteoporosis, fibromyalgia, arthrosis, and psychological problems (that had been consulted for). Missing values were defined as the absence of that disease/condition.

## 3.3.4 Measurements used in Papers I, II and III

The history of WHODAS 2.0 has been described in section 1.2.3 of this thesis. The instrument assesses disability during the previous 28 days (30 in the original) in 6 functional domains [16]: Cognition (6 items), Mobility (5 items), Self-care (4 items),

Getting along (5 items), Life activities (8 items), and Participation (8 items) [16]. Life activities consists of activities relating to the household (4 items) and those relating to work or study (4 items). Each item is scored on a 5-point Likert scale with two anchor responses, 'None' and 'Extreme or cannot do'. Scores for each domain and a total disability score were calculated according to the WHODAS 2.0 manual, using 'complex scoring' [16] ranging from 0 (no disability) to 100 (full disability). All 36 items are calculated for a total score in people who are working or studying. Otherwise, the four items related to work or study are omitted and 32 items are computed for the total score. An algorithm enables calculation of the domain score for Life activities and total score, regardless of whether the four items relating to work or study are answered. The following measurement properties were tested during the development process of the instrument: good reliability and item response characteristics, unidimensionality of domain, and two-level hierarchical structure, with one general disability factor feeding into the six domains [16]. The WHODAS 2.0 has been subsequently tested in other populations with chronic conditions and in a convenience sample of rehabilitation patients, supporting its adequate measurement properties [76, 77]. Permission to use this instrument was granted from the WHO.

The SF-36 is one of the world's most used instruments for measuring HRQoL [29]. The instrument consists of 36 items or questions which sum up to 8 domain scores representing different aspects of health, with scores from 0–100 in which 100 is the best possible HRQoL. An alternative method is to sum the items in two dimensions, to yield a mental and a physical component score. The following domains are included: mental health (5 items), vitality (4 items), bodily pain (2 items), general health (5 items), social functioning (2 items), physical functioning (10 items), role limitation related to physical problems (4 items), and role limitation related to emotional problems (3 items). Additionally, one item assesses changes in general health over the past year. The measurement properties of this instrument have been tested extensively, and the SF-36 has been shown to be a valid measure of health status across a wide range of patients [78], with adequate and high reliability [79, 80]. Additionally, normative data from the Norwegian population exists [81, 82].

The EQ-5D-5L is an instrument for use as a measure of health outcome [83]. The instrument is twofold, a questionnaire and a visual analogue scale. Respondents answer items in five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) ranging from no problems to extreme problems or distress. The responses are scored on a 5-point ordinal scale from 1 to 5, where a score of 1 is best. The instrument has been tested extensively for its measurement properties in other populations with chronic conditions [84]. Permission to use this instrument was granted from the EuroQol Group.

Symptoms of anxiety and depression were assessed with the HADS [85]. This instrument comprises two subscales, depression (HADS-D) and anxiety (HADS-A), with seven questions each; responses are scored on a scale of 0–3. For each subscale, the score ranges from 0 to 21 (higher score for greater severity). The instrument performs well as a screening instrument in assessing symptom severity in somatic patients [86]. HADS shows adequate measurement properties in terms of validity and reliability, and a two-factor structure model is supported [87].

The SOC-13 comprises 13 items in 3 subscales: comprehensibility (5 items), manageability (4 items), and meaningfulness (4 items). The patient scores each item on a 7-point Likert scale with two anchor responses, 'Never' and 'Very often'. After reversing 5 negatively formulated items, all items are summed to yield a score ranging from 13 to 91; higher scores indicate stronger SOC. The SOC-13 has generally acceptable reliability and validity [72, 88, 89]

Table 2 Overview of sociodemographics and health status data in Papers I, II and III

	Categorization / Item scoring	Paper	
Sociodemographic variables			
Sex	Male or female	I, II, III	
Age	Decades	II, III	
Health condition	Musculoskeletal, circulatory, neurological, neoplasms or other	II, III	
Multimorbidity	Yes or no	I, II, III	
Marital status	Married or unmarried	II, III	
Education	Primary, secondary or college/university	II, III	
Smoking	Current smoker or not	II, III	
Municipality	Urban or rural	II, III	
Physical fitness	Poor, moderate or good	II	
Standardised PROs			
WHODAS 2.0	0 - 100, 0 = no disability 100 = highest disability	I, II, III	
SF-36	0 - 100, 100 = best possible HRQoL	I, III	
EQ-5D-5L (pain/discomfort)	1-5, 1 = no pain/discomfort 5 = highest pain/discomfort	II, III	
HADS	0-21, 0 = no distress 21 = highest distress	II, III	
SOC-13	13 - 91, $91 = best possible$	III	

Abbreviations: PROs, patient-reported outcomes; WHODAS 2.0, World Health Organization Disability Assessment Schedule version 2.0; SF-36, Medical Outcomes Study Questionnaire Short Form 36 Version 1; EQ-5D-5L, European Quality of Life Scale Five Dimension Five Level Scale; HADS, Hospital Anxiety and Depression Scale; SOC-13, Sense of Coherence 13-item questionnaire.

## 3.3.3.1 Missing values

Missing items were treated according to the manuals and methods described in the literature. If the rate of missing WHODAS 2.0 items was > 50%, the case was

excluded. Multiple imputation (MI) for missing items was applied, according to the WHODAS 2.0 manual [16], with the number of imputation sets = 5. Missing items in the SF-36 were managed according to the SF-36 manual [90]. For the HADS and SOC-13, scores for patients with less than three missing questions per subscale were included. For missing data, scores were imputed based on the mean across each person's available responses for each subscale.

# 3.4 Analyses

For statistical analyses in Paper I, IBM SPSS version 22 (IBM Corp., Armonk, NY, USA) was used in addition to RStudio version 099.879, lavaan package 0.5-20 (RStudio, Inc., Boston, MA, USA). All statistical analyses in Papers II and III were conducted using IBM SPSS version 23. Additionally, RStudio version 1.0.143 was used in Paper III with lavaan package 0.5-23.1097. For all papers, the level of statistical significance was set to 5%. The exact chi-square and Mann–Whitney *U* tests were used to compare the female proportion and age between participants and nonrespondents in Papers II and III.

## 3.4.1 Paper I

Feasibility was assessed by exploring missing items of the WHODAS 2.0. A rate of 10 % missing items was used as critical [77]. A floor effect (lowest possible score) and ceiling effect (highest possible score) were defined if more than 15% of participants attained these scores.

Evaluation of the measurement properties of WHODAS 2.0 followed the taxonomy, terminology, and definitions of COSMIN [32].

For reproducibility, intraclass correlation coefficients (ICC) with a value of 0.7 are defined as acceptable [91]. The smallest detectable change (SDC) for domain scores and total score was estimated using the following equations [91]:

Standard error of measurement (SEM):

Standard Deviation (*SD*) from the first test  $\times \sqrt{1 - ICC}$ 

SDC:  $1.96 \times SEM \times \sqrt{2}$ .

Cronbach's alpha was estimated as a measure of internal consistency with a coefficient between 0.70 and 0.95 considered satisfactory [91]

Construct validity was explored using predefined expected correlations (Pearson's r) between scores of the WHODAS 2.0 and SF-36. Vegard Pihl Moen and Mari Klokkerud prepared these correlations. Twelve hypotheses of expected correlation were chosen for the analysis; the intervals for expected correlations were < 0.3, between 0.3 and 0.6, and > 0.6. The validity was considered high if fewer than three (25%) of the hypotheses were rejected, moderate with 25–50% and low with more than 50% of the hypotheses rejected [92]. In addition to the expected correlations, confirmatory factor analysis (CFA) was conducted to test if the data fit the original hypothesized structure of WHODAS 2.0. For CFA, the following cut-offs were used to define a satisfactory model fit: relative chi-square < 5 [93], comparative fit index (CFI) close to 0.95 or higher, root-mean-square error of approximation (RMSEA) close to 0.06 or lower, and standardised root mean square residual (SRMR) close to 0.08 or lower [94].

A priori formulated hypotheses were used to explore responsiveness. Eight hypotheses were tested using Mann–Whitney's U test, and hypotheses were formulated based on changes that were anticipated to occur. The same cut-off as for construct validity in terms of rejected hypotheses was used to define low, moderate and high degree of responsiveness. Moreover, effect size (ES) and standardised response mean (SRM) were calculated for domain scores and total scores of WHODAS 2.0 and SF-36 [95-97]. An ES of 0.2 is regarded as low, 0.5 as moderate, and 0.8 as high [98].

In addition to the analyses published in the paper, CFA was performed on a first-order six-factor model, as the factor structure is debated [48]. Furthermore, CFA of an adjusted model of WHODAS 2.0 was conducted, both first and second-order structure, excluding the item concerning sexual activity. This item has been reported to load higher on another factor, Participation [48, 76], and there was a relatively high number of missing responses for this item in the present study. Finally, CFA for the original hypothesized structure of WHODAS 2.0 was performed for diagnostic groups in which the subjects-to-variables ratio was > 5 [99].

#### 3.4.2 Paper II

Descriptive statistics of the WHODAS 2.0 total score and scores of the six domains were estimated according to categories of the different predictors and were reported using mean/median and standard error (SE). The exact chi-square test and Mann—Whitney's *U* test were used to investigate differences in female proportion and age between participants and nonrespondents. For variables with more than two categories, analysis of variance (ANOVA) with the F-test was conducted to investigate differences in disability scores (Tukey's post hoc test for subgroup comparisons).

Linear regression analyses were performed to analyse the total disability score and score of the domains separately as response variables. Predictor variables were: sex, age, health condition, multimorbidity, marital status, education level, smoking status, municipality of residence, physical fitness, EQ-5D (pain/discomfort), HADS-D score, and HADS-A score. All variables except the scores for EQ-5D (pain/discomfort), HADS-D, and HADS-A were treated as categorical variables; otherwise, variables were treated as continuous.

First, one predictor was analysed at a time; thereafter, all predictor variables were included simultaneously. For domains, only adjusted results were presented. Results were reported as the estimated regression coefficient (b), 95% confidence interval (CI) or SE, and p-value from the F-test. The distribution of residuals was checked for adherence to the assumptions of linearity, normality, and variance homogeneity.

First, one predictor was analysed at a time; thereafter, all predictor variables were included simultaneously. For domains, only adjusted results were presented. Results were reported as the estimated regression coefficient (b), 95 % confidence interval (CI) or the SE, and p value from the F-test. The distribution of residuals was checked for adherence to the assumptions of linearity, normality, and variance homogeneity.

Additionally, for the analyses in the published paper, patients were categorised based on their WHODAS 2.0 total disability score according to ICF disability levels [42]

## 3.4.3 Paper III

Mean and SD are reported for descriptive statistics. To study the effect of SOC on domain-specific disability, multiple linear regression was performed. Estimated regression coefficients with 95% CI and p-values from the F-test were reported. The distribution of residuals was checked for adherence to the assumptions of linearity, normality, and variance homogeneity. To investigate differences in SOC scores for variables with more than two categories, ANOVA with the F-test was conducted and Tukey's post hoc test was performed for subgroup comparisons.

Structural equation modelling was performed for two hypothesized models for the relationships between the variables SOC, disability, and HRQoL (Figure 2). Listwise deletion was applied when conducting SEM. Satisfactory model fit was defined as CFI close to 0.95 or higher, Tucker–Lewis Index (TLI) close to 0.95 or higher, RMSEA close to < 0.06 or lower, cut-off close to 0.08 or lower, and SRMR close to 0.08 or lower [94]. Regression coefficients were examined for statistical significance, and estimated model parameters with 95 % CI are given.



Figure 2 Hypothesized structural models for SOC, HRQoL and disability

The regression and the SEM were performed for the full sample and separately for each of the diagnostic groups.

In addition to the analyses in the published paper, Pearson's correlation (r) was calculated for the WHODAS 2.0 total and domains scores versus SF-36 physical and mental component scores.

## 3.5 Ethical considerations

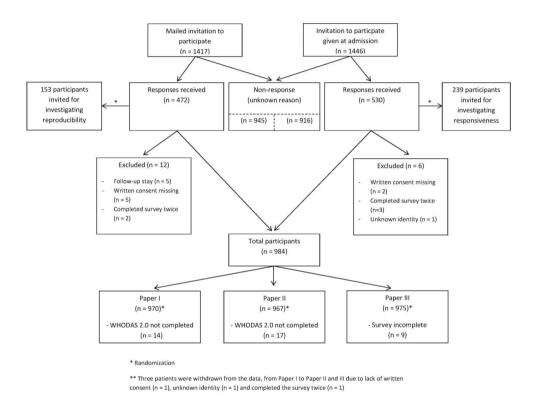
This study was approved by the Regional Committee for Medical Research Ethics in Western Norway, REK-No. 2014-1636. Written informed consent, which included linkage with public register data, was obtained from all study participants.

The burden on respondents by completing a relatively comprehensive questionnaire concerning their health was discussed in terms of ethics. Consequently, the most important aspects to ensure comprehensiveness and comparability while minimizing the extent of the questionnaire were included by the research group when constructing the questionnaire.

## 4. RESULTS - SUMMARY OF PAPERS

# 4.1 Participants

A flow chart of participant invitation, inclusion, and exclusion is shown in Figure 3.



**Figure 3** Flow chart of participant recruitment and inclusion and exclusion in Papers I, II and III

The mean participants age (SD) in Papers I, II and III was 57.7 (14.1) years, 57.6 (14.0) years, and 57.6 years (14.0), respectively. The proportion of women was 63.2% in all three papers. Musculoskeletal diseases were reported as the main health condition in approximately 50% of participants, circulatory diseases in approximately 20%, neurological diseases in approximately 10%, neoplasm in approximately 5%, and other diseases (merging all diseases with 10%) in approximately 10%0 of

respondents. For nonrespondents, the mean age (SD) was 55.6 (16.7) years and 67.2% were women, significantly different from participants (p < 0.001 and p < 0.05, respectively).

The data were not completely assured for quality at the time that Paper I was finished and published; hence, no flow chart or detailed specification was included in Paper I. After quality assurance of the patient flow, 13 participants fulfilled the inclusion criteria and 18 the exclusion criteria, as reported in Papers II and III. In addition, one patient who met the exclusion criterion of a follow-up stay was registered. These findings were discovered when the 1-year follow-up was conducted and in the process of obtaining registry data.

#### 4.1.1 Results of Paper I

The number of missing values was between 0.3% and 5.5% for all WHODAS 2.0 items, except the item concerning sexual activities (10.4%). No ceiling effect was present, but floor effects were present in the following three domains: Cognition, Selfcare and Getting along. Further details are presented in Table 2 Paper I.

A sample of 153 participants was invited to explore the reliability of the WHODAS 2.0 by reproducibility by completing WHODAS 2.0 a second time. Nearly 75% (n = 113) responded and 53 participants (46.9% of the respondents) fulfilled the criteria for inclusion in the analysis. The mean test–retest period was 11.6 days. The ICC was 0.63–0.87, lowest for Self-care and highest for total score. SDC for total score of the WHODAS 2.0 was 16.2 and 22.8 to 35.8 for domains. Further details can be found in Table 2 of Paper I. For internal consistency, Cronbach's alpha was > 0.7 for the total score and domains.

For construct validity, the overall agreement for predefined expected correlations was 77.8%, with 48 correlations in total. Total agreement was reported between the WHODAS 2.0 domain Getting along and SF-36 domains; for the WHODAS 2.0 domain Participation, agreement was found for 5 of 8 correlations. Of the 12 predefined correlations to assess responsiveness, 6 were confirmed (Table 3 Paper I).

The results of CFA for the whole sample showed a good fit for the second-order six-factor structure defined in the WHODAS 2.0 manual [16]. Additionally, unpublished results from the CFA for adjusted structure, both for the full sample and the largest diagnostic groups, are shown in Table 3.

 Table 3 Results for confirmatory factor analysis of original and adjusted models of WHODAS 2.0 for

full sample and two diagnostic groups

	Structure	$\chi^2/df$	RMSEA, 95% CI	SRMR	CFI
Full sample <sup>a</sup>					
	First-order 6-factor	5.30	0.066 (0.064, 0.069)*	0.067	0.883
	Second-order 6-factor	6.35	0.074 (0.071, 0.077)*	0.094	0.851
Full sample <sup>b</sup>					
	First-order 6-factor	5.34	0.067 (0.064, 0.070)*	0.062	0.888
	Second-order 6-factor	6.49	0.075 (0.073, 0.078)*	0.094	0.856
Diagnostic groups <sup>c)</sup>					
Diseases of the	First-order 6-factor	3.13	0.068 (0.064, 0.072)*	0.075	0.868
musculoskeletal	Second-order 6-factor	3.75	0.078 (0.074, 0.082)*	0.104	0.837
system and					
connective tissue					
Diseases of the	First-order 6-factor	2.03	0.075 (0.068, 0.082)*	0.079	0.863
circulatory	Second-order 6-factor	2.24	0.082 (0.075, 0.089)*	0.092	0.841
system					

Abbreviations: WHODAS 2.0, World Health Organization Disability Assessment Schedule version 2;  $\chi 2/df$ , relative chi-square ( $\chi 2$ , chi-square; df, degrees of freedom); RMSEA, root mean square error of approximation; C, confidence interval; SRMR, standardised root mean square residual; CFI, comparative fit index.

A sample of 239 patients was invited to participate in an investigation of short-term responsiveness of the WHODAS 2.0. Of these, 138 patients responded (57.7%) and 104 fulfilled the criteria for inclusion in the analysis. The mean period between these assessments was 48.4 days. Three of eight a priori formulated hypotheses were confirmed (Table 4, Paper I). For WHODAS 2.0, the ES ranged between -0.07 and -0.25 for the domains and -0.27 for the total score. The SRM ranged between -0.10 and -0.33 for domains and -0.36 for the total score. For the SF-36, the ES and SRM were higher, 0.18–0.47 and 0.16–0.56, respectively. In comparison to change scores, all SDCs were higher for their respective domain or total score.

a) original model, i.e. 32-item version of WHODAS 2.0 (without items concerning work/study).

b) adjusted model, i.e. as in a) but exclusion of item D4.5 concerning sexual activity.

c) original model, i.e. 32-item version of WHODAS 2.0.

<sup>\*</sup> all RMSEA, p < 0.001.

## 4.1.2 Results of Paper II

The mean (SE) overall disability score was 30.0 (0.5). The highest total disability score was reported for patients aged 40–49 years. Neurological diseases had the highest total disability score. More details are given in Table 1 of Paper II. According to ICF disability levels, 2.0% of participants were categorised with no problems, 38.4% with mild problems, 49.1% with moderate problems, and 10.5% with severe problems.

The presence of multimorbidity, initial rehabilitation, low education level, poor physical fitness, higher pain/discomfort, and higher scores for depressive symptoms were all significantly associated with higher total disability scores (Table 2, Paper II). In addition, patients with neurological diseases had significantly increased total disability scores.

The results from the multivariate multiple linear regression model (Table 3 Paper II) showed that better physical fitness and lower distress resulted in lower disability scores for most domains. Whereas patients with neurologic diseases scored significantly higher in most domains, lower disability scores were reported for Cognition and Getting along in patients with neoplasm.

Higher scores for anxiety symptoms were associated with higher disability scores in Cognition, Getting along and Participation, and lower disability scores in Mobility and Life activities.

## 4.1.3 Results of Paper III

Mean scores (SD) were 62.9 (12.3), 30.8 (16.2), 32.8 (9.6) and 43.6 (11.8) for SOC - 13, WHODAS 2.0, SF-36 physical component, and SF-36 mental component, respectively. More details are shown in Table 1 of Paper III. Scores for the main variables could not be calculated for nine patients. WHODAS 2.0 scores could be calculated for 967 patients, SF-36 scores for 885 patients, and SOC scores for 933 patients.

Higher SOC-13 score was associated with lower disability scores in the following domains with estimated regression coefficients (95% CI): Cognition -0.20 (-0.32 to -0.08), Getting along -0.36 (-0.52 to -0.25), and Participation -0.23 (-0.36 to -0.11) (Table 2, Paper III).

Getting along was the domain in which all diagnostic groups, except circulatory diseases, were associated with SOC, with increased disability scores for lower SOC-13 scores (Table 3, Paper III).

The results from the structural equation modelling showed that fit was better for the mental versus the physical component of HRQoL, with numerically similar fit indices for both models (Table 4 Paper III). Only three diagnostic groups had large enough number of participants for estimable structural models. For both models, good fit was reported for circulatory diseases (CFI and TLI > 0.95, RMSEA < 0.06) (Table 4 Paper III) and less good fit for musculoskeletal diseases. All models were significantly better than the independent model.

For the correlation between WHODAS 2.0 domains and SF-36 component scores, r was highest for WHODAS 2.0 Mobility versus the SF-36 physical component score and for WHODAS 2.0 Participation versus the SF-36 mental component score, with 0.67 and 0.54, respectively. All other r values were < 0.5.

## 5. DISCUSSION

This study is based on data from the largest survey so far of patients entering rehabilitation centres in Norway. Because the knowledge basis of health characteristics among these patients as a group is sparse the overall aim was to increase this basis.

A survey of this scale, including all patients with various health conditions entering rehabilitation centres and using generic instruments, has not been conducted previously; hence, ensuring the quality of the chosen instrument was required, to determine its attributes when measuring the most common characteristic among rehabilitation patients, namely, disability. Furthermore, we aimed to improve our understanding of the factors associated with disability and the role of SOC in rehabilitation by investigating disability and predictors of disability, and by analysing the relations between SOC, disability, and HRQoL. The present results may be valuable when developing strategies to improve the health of people with disabilities, as well as for disability research in general.

The main findings of the study showed that WHODAS 2.0 can be considered an important instrument with valuable measurement properties for investigating disability among patients entering rehabilitation centres in Norway. Patients reported relatively low total disability scores. The highest disability domain scores were reported for Life activities and Participation; the latter has been investigated to a limited degree in rehabilitation settings.

As a consequence of the fact that the patients entering rehabilitation centres are a select group with relatively low disability scores, as most patients must be able to care for themselves, previously reported predictors of disability, such as age and sex, are of minor or no importance to disability among the study population. Finally, targeting and strengthening the patients' SOC may reduce disability in the domains with mental components as well as increase the mental components of HRQoL. However, the role of SOC in relation to disability and HRQoL may vary among diagnostic groups.

# 5.1 Methodological considerations

#### 5.1.1 Validity aspects

#### 5.1.1.1 Design

The well-planned design of all studies in this thesis ensures relevance of the data as data collection procedures were established prior to the studies being commenced. All papers in this thesis use data from a cross-sectional study. An advantage of a cross-sectional design is simultaneous collection of data, enhancing the precision of the association between the variables of interest. Contrarily, a disadvantage of this design is the inability to determine causality.

All instruments used in this thesis are acknowledged and widely used and have been validated in Norwegian settings, showing sound measurement properties. This ensures high-quality data in terms of measuring the construct of interest. Questionnaires were completed either at centres or at home. To minimise information bias, survey administration should preferably be similar for those invited by mail and those recruited at centres. Use of a 4-week recall period for many items in the WHODAS 2.0 and SF-36 may be challenging for patients referred from hospitals because most of these patients have not been at home during the previous 4 weeks, so they may have difficulty with rating their disabilities/problems in performing certain activities. We have no data of their reference frame, i.e. whether items were scored using their best period as a reference or their worst period. For HADS, EQ-5D-5L, and SOC-13, the items are related to the respondent's situation at the time of completion, with no specification of time.

The context dependency is important when measuring disability using an instrument. For this thesis, environmental restrictions are not known to influence the assessment of disability by WHODAS 2.0.

Patients recruited at admittance to the rehabilitation centres were not invited to complete the WHODAS 2.0 a second time because rehabilitation interventions at the centres would have occurred during the test–retest period. Hence, a response shift

[100] (i.e. a change within people regarding internal standards, values, or conceptualization of disability) is mostly absent from the results of the test–retest analysis.

#### 5.1.1.2 Sample

There is nonresponse bias in all three papers. The response rate of 34.6% indicates a large group of nonrespondents. However, the response rate is a conservative estimate. Patients were invited both at admittance to the centres and through a waiting list. Consequently, although all research assistants were trained, some patients who were registered from the waiting list may have been registered at admittance as nonrespondents. Although rehabilitation centres were contacted regarding duplicate registrations after the inclusion period, these patients could not be discovered owing to limited information of nonrespondents (age and sex).

To ensure validity of the results of a health survey, it is essential to retain a sufficient number of participants. A high response rate has been considered a feature of good epidemiologic study execution [101-103]. However, it has been argued that response representativeness is more important than response rate [104]. Differences in age and sex between respondents and nonrespondents, which were reported in Papers II and III, indicate a nonresponse bias [105] as missing data are likely from a biased patient subset [106]. Consequently, this weakens the external validity. Participants were significantly older compared with nonrespondents, which agrees with trends in questionnaire-based research [107]. The difference in attitudes towards surveys in different cohorts may explain this. This may imply that the reported scores of the SOC-13, SF-36 mental component, and WHODAS 2.0 Mobility are higher than one would expect whereas scores of WHODAS 2.0 Cognition and Participation are lower. Although high response rates are often associated with higher validity of the results in survey research, this is not straightforward. If the nonrespondents are a relatively homogenous group that differs markedly from the respondents, significant bias occurs despite high participation rates [104]. The response rate from the seven rehabilitation centres ranged from 19.4% to 91.7%. Hence, some patient groups are more likely to be representative of the total sample.

Considering health conditions, statistics reported by the Norwegian Directorate of Health [6] reveal that most patients at rehabilitation centres are referred for a musculoskeletal disease, indicating that the study sample is somewhat representative in terms of diagnoses. Additionally, these statistics also show a higher proportion of women entering rehabilitation at Norwegian centres in secondary care [6]. Furthermore, the relatively high functional level reported among the study population was expected and is in line with the requirement specifications of services contracted with the rehabilitation centres, in other words, most patients entering rehabilitation at these centres must be able to care for themselves.

There is no reason to believe that the results of this study would differ in other regions of Norway; therefore, the present study findings are likely to be generalisable to patients entering rehabilitation centres in other regions in the country. Although rehabilitation centres have made some adjustments to the requirement specifications in recent years with the aim to rehabilitate patients with more severe disabilities and a greater need for assistance, this group of patients is still small compared with the total population who enter Norwegian rehabilitation centres. Hence, the results are valid for patients being rehabilitated at these centres today. In addition, the health conditions which are reported in this study are not explicitly for patients entering rehabilitation centres in secondary care, but also in the health services on all levels; hence, the findings of this study are probably relevant for people with chronic diseases in general.

Differences in rehabilitation practices, health care, and welfare limit the generalisability of the study results to other countries. Many countries do not offer rehabilitation at specialised rehabilitation centres [108]. Only Germany and some Eastern European countries may have aspects that are comparable with Norwegian rehabilitation centres [108, 109].

#### 5.1.2 Statistical methods

Single-imputation and MI were used for handling missing values. The single-imputation method may lead to underestimation of the variance of the estimates for SF-36, HADS, and SOC and therefore may overstate precision and may result in CIs

and significance tests that are overly optimistic. In contrast, MI used for WHODAS 2.0 rectifies this problem by creating multiple data sets, taking into account the sampling variability owing to the missing values (between-imputation variability) [110]. MI strengthens the validity of the estimates for the respondents reported in the papers, i.e. disability estimates. The low proportion of missing values reported in this study is a strength. Because MI creates several different plausible imputed data sets based on the observed data, multivariate regression analysis was conducted in Paper II. Consequently, the multivariate analysis, in which dependent variables are associated with each other, and the use of MI may have strengthened the relationship between predictor variables and disability domains in Paper II.

For Paper III, the two summary scores of SF-36 were used as outcome measures. Among people with chronic conditions, as well as in general populations, these scores account for 80%–85% of the reliable variance in the eight SF-36 scales for physical and mental components of health [64]. Hence, this simplified the number of statistical comparisons without substantial loss of information.

The inclusion of many variables in the multiple regressions of Papers II and III may limit the significant findings. Estimation of many unknowns (i.e. many degrees of freedom) in multiple regression analysis may result in finding complicated relationships (interactions, nonlinear effects) between the predictors and the response variable that exist in the sample but not in the population. Moreover, the power to detect true relationships may be reduced. However, all the included predictor variables have been shown to be associated with the outcome variables of interest.

In Paper III both depression and SOC are included in the regression model. It has been suggested that these constructs are highly associated which may imply multicollinearity. However, a previous study shows that these two construct are not the same [111].

Among other measures of reliability, the ICC was used to assess reliability. The ICC is highly dependent on heterogeneity. Because the heterogeneity of patients under investigation largely determines the value of the ICC, if variance is low, the ICC is

likely to be low [112]. Hence, this emphasizes that the results are generalizable only to samples with a similar variation.

## 5.2 Discussion of the main findings

## 5.2.1 Measurement properties of WHODAS 2.0 (Paper I)

WHODAS 2.0 is recognised to be the current leading measure of disability worldwide [48]. We investigated the measurement properties of WHODAS 2.0 among patients accepted for rehabilitation at a rehabilitation centre in secondary care in Norway. The results of this study are consistent with previous studies showing moderate to satisfactory reliability and moderate validity of the instrument. The low responsiveness may indicate a limitation in terms of measuring changes over time.

The presence of floor and ceiling effects has been reported in previous studies with similar diagnostic groups [76, 113-115]. In this study, no ceiling effect was found and floor effects were reported in three of six domains, implying difficulties in differentiating patients with low levels of disability. Ceiling and floor effects might indicate low variance between patients, and hence, could influence the ICC when reliability is assessed. Except for the domain Self-care, acceptable reproducibility was reported for total and domain scores. This supports the use of WHODAS for group comparison. Previous studies have reported ICCs between 0.62 and 0.97 [76, 114-117]; however, the ICC in the present study did not reach the required cut-off of 0.9 for individual comparison [118].

Construct validity, investigated by means of expected correlations between the WHODAS 2.0 and SF-36, was considered moderate compared with the SF-36. In previous studies, moderate and strong correlations have been reported, both expected and not predefined [76, 77, 116, 119, 120]. In addition, a review from 2017 reported moderate and strong correlation between WHODAS 2.0 and patient-reported outcome measures (PROMs) of health such as the World Health Organization Quality of Life [48].

The second-order six-factor structure of WHODAS 2.0 described in the manual [16] did not reach satisfactory fit in this study, and a first-order structure was slightly better. Previous studies have shown lower fit indices than the proposed satisfactory cut-off used in Paper I [76, 113, 114, 119], indicating some degree of misfit with the original structure. Moreover, cross-loadings may indicate partial conceptual overlap between the domains of WHODAS 2.0 [121]. Notwithstanding, for comparison reasons, Paper I emphasizes that the original structure should be retained.

Assessing responsiveness is debatable as there is no gold standard, and to the author's knowledge, this is the first paper evaluating this measurement property of WHODAS 2.0 by testing a priori hypotheses. The results showed low responsiveness of the WHODAS 2.0. This was to some extent expected because the instrument is generic, and contrary to rehabilitation, specific domains which patients list as most important may not be targeted. However, some aspects need to be considered. First, the heterogeneity of diseases challenges the formulation of hypotheses because various domains are important for various diagnostic groups. Mobility was included in three of eight hypotheses and may have led to underestimation of responsiveness. Second, rehabilitation at the various centres may target different domains than those captured by WHODAS 2.0. Third, the assessment period, 4 to 13 weeks after discharge, may be too late or too early to measure changes [77, 122]. Fourth, on the individual level, use of a generic questionnaire may reduce the possibility of capturing change because the individual's most important disability domain might not be addressed in the instrument. Fifth, a single minimal clinically important difference (MCID) has not been established [48] and a cut-off could not be linked to the global question exploring self-perceived change. This means that we were unable to identify the subgroup that scored higher than the MCID.

Despite all these aspects challenging the evaluation of responsiveness with hypotheses, there are some aspects of note regarding our assertion. First, the content in rehabilitation has been investigated in a Norwegian population with musculoskeletal diseases, with patients reporting many group sessions in their rehabilitation, not only individual sessions [123]. Consequently, domains other than the individual's most

important disability domain are targeted. Second, the organization of current rehabilitation services was developed based on contracts with requirements specifications, i.e. patients are referred to rehabilitation centres which aim to target certain disability domains stated in the contracts, not only the individual's most important domain.

Assessing responsiveness has by calculating EF and SRM are useful when there are no available anchor-based measures [124]. However, these measures have limitations since they cannot reflect a true change, but rather a change in general or a clinically important change [97]. The results from Paper I show a positive short-term change, with low and moderate values of ES and SRM for the full sample. This is similar to and lower than those of previous studies [76, 77, 119, 125], which may be explained by different study samples and different assessment periods. However, with higher SDC than change scores and a lack of MCID, measurement of change scores with WHODAS 2.0 beyond measurement error and that is clinically meaningful for patients is challenging.

In summary, using WHODAS 2.0 in rehabilitation seems inappropriate for capturing short-term changes. However, the instrument has important features for assessing disability. This is in line with results from a workgroup that was established in 2017 by the Norwegian Directorate of Health, which aimed to propose generic functioning tools for rehabilitation in secondary care and possibly also in primary care. In January 2018, a report was published with the workgroup's recommendations [126], and WHODAS 2.0 was ranked among the top three currently recommended instruments as a result of being based on the ICF, having adequate measurement properties, and ease of administration.

# 5.2.2 Distribution of disability and the most important predictors (Paper II)

The most common characteristic among rehabilitation patients is disability. Paper II aimed to investigate the distribution of WHODAS 2.0 disability scores among patients entering rehabilitation at a Norwegian rehabilitation centre in secondary care and to

investigate predictors associated with disability. The main findings of this study are the variation between domain scores, with the highest domain scores for Life activities and Participation. In addition, there was variation in terms of predictors for total score and domain scores.

The total disability score, as assessed by the WHODAS 2.0, of approximately 30 out of the maximum of 100 may be considered relatively low, if considering 45 as the limit for substantial disability [33]. However, in comparison with a multicentre study investigating disability among clinical samples from seven European centres, the present study found higher WHODAS 2.0 total scores and higher values for most domain scores [76]. A comparison of SF-36 scores also showed this difference, with lower health scores for this study population (Paper I). In comparison with a convenience sample of patients entering rehabilitation in Germany, our study sample mostly showed higher domain scores for all comparable diagnostic groups [77]. However, comparing disability scores may be challenging because of contextual factors, including different health systems and time trends. When counting individuals with a certain characteristic, nearly 60% of patients were categorised with moderate or severe disability according to ICF disability levels [42], and approximately 40% had mild disability or no/negliable problem.

A linear trend is often seen between age and disability, with increasing disability according to increasing age [127-129]. However, no association was found in this study between age and total disability score; as a consequence, age was categorised according to decades. This finding must be seen in light of the criteria for admission to rehabilitation centres. In practice, older people with both cognitive and physical disabilities are referred to rehabilitation in primary care, and they are somewhat excluded from these centres. Higher disability scores for the domain Mobility and lower disability scores for Cognition were found with older age. Women generally score higher for disability [130-135]; this was not found in our study, except for the domain the domain Life activities. A previous study suggested that this finding in this domain may reflect the traditional gender roles concerning the household [131].

The requirement specifications for rehabilitation centres, which explains the low score for Self-care as most patients must be able to care for themselves in these centres, implies that the sample was homogenous to some extent concerning disability score, despite a wide range of diseases. However, disability varied among health conditions, which is consistent with previous studies [131, 136, 137], with high scores for patients with neurological diseases in the domains Mobility and Life activities. For neoplasms, high scores were reported for Cognition and Getting along. This may be explained by cognitive difficulties and fatigue, which have been reported after cancer treatment [138, 139].

The presence of multimorbidity increased disability score which is in line with previous studies [132, 140, 141]. No association was found for Mobility, in contrast to previous reports. This is likely the result of the exclusion of patients with severe disabilities.

A study among adults with arthritis reported physical fitness and pain to be predictors for disability [142]. This is in accordance with our findings, except for domains with mainly cognitive components, Cognition and Getting along. This means that performing daily cognitive tasks is not affected by pain or physical fitness.

Psychological distress has been reported to predict disability [132, 140, 143]. Our results show that symptoms of depression are associated with disability for all domains. For symptoms of anxiety, the results vary, with positive and negative effects on disability. In older populations, symptoms of anxiety have been reported to increase disability only in women. Future studies in larger populations may clarify the association between symptoms of anxiety and disability since this is less investigated.

The safety net of social welfare services in Norway is well developed to help people with disabilities regain active and productive lives as well as to participate at home and in the community. The domain Participation is less frequently investigated than other domains because measures of participation are less developed [18]. In our study, scores for Participation were compared with those of other domains. In the ICF, this domain addresses participation restrictions defined as 'problems an individual may

experience in involvement in life situations' [42]; WHODAS 2.0 addresses environmental barriers, societal attitudes, and emotional and economic distress, among others. These factors are related to social structures and are not primarily targeted by health services. However, a comprehensive understanding of participation restrictions contributes to viewing problems as rooted in the structures surrounding the patients; the results of the adjusted model showed that this is important for all health conditions. Factors associated with this domain, physical fitness, and education may be explained by experiences with physical barriers and the universally positive effect on all forms of civic and social engagement [144].

## 5.2.3 The role of SOC in rehabilitation (Paper III)

As revealed in Paper II, awareness of predictors, is important for reducing disability. Additionally, focusing on people's inherent resources and enabling them to participate actively is important when promoting health. Hence, the relationships between SOC, disability, and HRQoL were investigated. As for clinical relevance, the diagnostic groups were analysed separately.

The mean SOC-13 score found in the present study was higher than that in a Norwegian population of working-age patients who had chronic, nonspecific musculoskeletal pain [145]; the present score was also slightly lower than that in a Norwegian population of women discharged from hospital after myocardial infarction [146]. At diagnostic group level, our results are in line with these studies, with higher SOC-13 scores for circulatory diseases than musculoskeletal ones. The SF-36 domain scores for our sample (reported in Paper I) were lower than postrehabilitation scores among a population of rehabilitation patients in the Netherlands [147]. However, the higher scores in the Dutch study might be attributed to the effect of rehabilitation. In terms of disability scores, a comparison with other populations is provided in Paper II.

Antonovsky argued for an association between health and SOC, with better health associated with stronger SOC. We did not find an association between SOC and physical domains of disability; this is in accordance with a comprehensive review including 458 scientific publications and 13 doctoral theses reporting that SOC is less

associated with physical components of health than mental components [73]. Participation restrictions, which are less often investigated in disability studies, resulting in sparse knowledge of its relationship to SOC, showed an association with SOC. This may be explained by the fact that this domain addresses to some extent aspects that may represent social support, which is positively related to SOC [148]. Additionally, life orientation is shaped by the environment and reality, meaning that integration into social environments is strongly associated with SOC [68]. Consequently, interventions concerning SOC should be considered when developing strategies for targeting the domain Participation in rehabilitation.

Our results from the structural equation modelling in the full sample further support the relationship with health, with better fit of both hypothesized models for mental components of HRQoL compared with physical components. This implies that rehabilitation patients who perceive events as ordered, consistent, and structured are able to mobilise available resources to manage challenges of everyday life, and those who find this meaningful may have improved mental health. This is supported by a study where higher levels of SOC predicted improved mental health in men 3–6 months after myocardial infarction [149].

Fit indices from SEM varied among the diagnostic groups. The good fit indices for circulatory diseases suggest that the direction of association is from SOC to mental disability and mental components of HRQoL, consistent with findings from a study among adolescents with congenital heart disease [150]. To the best of our knowledge, adequate fit indices for the physical component of HRQoL have not been reported previously. For patients with musculoskeletal diseases, the fit indices did not support the hypothesized models and the role of SOC is unclear. A previous study among patients with chronic nonspecific musculoskeletal pain showed no association between SOC and work re-entry [145]; further investigation of the role of SOC for this diagnostic group is needed.

WHODAS 2.0 measures activity limitations and participation restriction, and SF-36 addresses the patient's physical and mental health. These constructs may overlap.

However, the correlations between the two component scores of the SF-36 and the domains of WHODAS 2.0 suggest that the correlation has certain similarities but is not equal. Nonetheless, the results of SEM, which were numerically similar, suggest a different causal role of SOC.

The authors of a study investigating the association between SOC and disability among an elderly population proposed an opposite direction of association between SOC and disability [151]. WHODAS 2.0 rates disability from the respondent's perspective and not from that of health professionals. This implies that activity limitations and participation restrictions including work and study, which are described in Paper II, may be perceived as stressors [152]. Individuals who fail to deal with these stressors may have their pre-existing SOC weakened. Findings from a 5-year prospective population-based study showed that people with disease were among those with the largest decrease in SOC scores over time [69]. Consequently, strengthening SOC should be addressed, and for musculoskeletal diseases, SOC may be enhanced via rehabilitation [145].

## 6. CONCLUSION

The work of this thesis aimed to increase the knowledge basis in terms of health status characteristics, especially those regarding disability among patients entering rehabilitation centres in secondary care. However, as similar diagnostic groups are found in the health services on all levels, the findings of this study are probably relevant for people with chronic diseases in general.

The first step was to ensure the quality of WHODAS 2.0 by evaluating its measurement properties. We found that this instrument, which was developed by the WHO and conceptualised in the ICF, is a valuable instrument for investigating disability among patients entering rehabilitation centres in Norway. Although disability is not a dichotomous or fixed state, the extensive use of WHODAS 2.0 in research worldwide is a great advantage when comparing data. However, the ability to capture short-term changes using WHODAS 2.0 seems to have some limitations.

For the first time, a large survey of nearly 1000 patients entering rehabilitation centres in Norway was conducted. Patients in rehabilitation centres have relatively low WHODAS 2.0 disability scores partly because they need to be able to care for themselves. Furthermore, this is the first time that the domain participation has been investigated among such a large group of rehabilitation patients in Norway as this domain is seldom, or to a minimal extent, included in PROMs assessing disability. Hence, the fairly high score in this domain reported here provides new insights of participation restrictions experienced by rehabilitation patients and should be considered when developing rehabilitation strategies.

In addition to the fact that many previously reported disability predictors were found, we also revealed that these vary among the different disability domains. However, greater depressive symptoms increased disability scores in all domains. Predictors of disability are valuable for gaining an understanding of possible factors to address.

Another approach to reduce disability and improve health is strengthening patients' resources. This strategy is emphasized by the national authorities. Paper III indicated

that SOC is associated with mental components of disability. The role of SOC in relation to disability and HRQoL may vary between the diagnostic groups. Targeting SOC in rehabilitation, especially in circulatory diseases, may improve mental components of both disability and HRQoL

# 7. FUTURE PERSPECTIVES

Integration of information about functioning is essential for development of rehabilitative strategies and according to our findings, we recommend the use of WHODAS 2.0 for measuring disability, including six important domains, among rehabilitation patients. Whether the instrument is appropriate for assessing outcomes of rehabilitation is of concern; cf. the result for responsiveness. However, because rehabilitation is a process that occurs over a period of time, long-term responsiveness of the instrument should be investigated.

Participation as a disability domain is less frequently investigated among rehabilitation patients and needs to be further explored. It is essential to understand the contextual factors that contribute to participation restrictions among rehabilitation patients, to enable community integration and independent living. This may provide us with valuable knowledge about whether rehabilitation in this domain is best targeted in primary care, in the setting where the person lives because of competence to the related community, or in secondary care at rehabilitation centres.

Gaining better control over life situations is emphasized for rehabilitation patients by the national health authorities. Therefore, the role of SOC in rehabilitation will be further investigated in the ongoing prospective study, i.e. the association with disability, HRQoL, and other important outcomes of rehabilitation, and whether the structural models assessed in this study are relevant for all diagnostic groups.

Follow-up of the participants in this study is ongoing. Collection of follow-up data will enable us to investigate predictors of disability and HRQoL in rehabilitation patients over the long term, among other factors including examining the causal effect of baseline SOC scores. Survey data have been collected

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# 9. APPENDICES

The approval from the Regional committees for medical and health research
ethics

 $\ \square$  The questionnaire used in baseline survey for collecting data used in this study



 Region:
 Saksbehandler:
 Telefon:
 Vår dato:
 Vår referanse:

 REK vest
 Arne Salbu
 55978498
 11.11.2014
 2014/1636/REK vest

 Deres dato:
 Deres referanse:

 23.09.2014
 23.09.2014

Vår referanse må oppgis ved alle henvendelser

Sturla Gjesdal Det medisinske fakultet Universitetet i Bergen

#### 2014/1636 Rehabilitering i Helse Vest

Det vises til din søknad 23.09.14 for nevnte prosjekt. REK vest behandlet saken i møte den 23.10.14.

Søknaden/protokollen reiser sentrale spørsmål omkring virkning av rehabilitering som det er viktig å få belyst, både av hensyn til den enkelte pasient og av hensyn til samfunnet. Vi ser en mulig svakhet i opplegget; «alle» som skal til rehabilitering kan inkluderes, man skiller ikke mellom diagnosegrupper. Med så store ulikheter det kan være mellom pasientgruppene som behandles i rehabiliteringsinstitusjoner, ser vi et mulig metodisk problem mht validitet. Man bør være seg bevist dette problemet og søke å minimalisere det.

Samtykke innhentes fra alle pasientene. REK vest har ingen merknader her. Imidlertid skal det også hentes inn opplysninger om de respektive fastlegene, dog ikke helseopplysninger. Innhenting og bruk av disse opplysningene, er ikke basert på samtykke fra fastlegene. REK vest setter som vilkår at fastlegene informeres om prosjektet og om hvilke opplysninger som vil bli hentet inn om dem.

Prosjektslutt: 31.03.2017.

Vilkår

-informasjon til fastlegene, jfr ovennevnte.

#### Vedtak

REK vest godkjenner prosjektet på betingelse av at ovennevnte vilkår tas til følge.

Med vennlig hilsen

Ansgar Berg Prof. Dr.med Komitéleder

> Arne Salbu rådgiver

 $\textbf{Kopi til:} \ edith.victoria.lunde@helse-bergen.no; \ margit.soerhus@helse-bergen.no; \ sturla.gjesdal@isf.uib.no$ 





#### Regionalt kompetansesenter for habilitering og rehabilitering

# Spørreskjema før rehabilitering ved rehabiliteringsinstitusjon

Hensikten med dette forskningsprosjektet er å få bedre kunnskap om personene som får tilbud om rehabilitering, og hvordan det går etter rehabiliteringsoppholdet. For å kunne gjøre dette vil det være nødvendig å spørre grundig om hvordan du har det nå før du starter med rehabilitering. Det er mange spørsmål i skjemaet. Det er ingen riktige eller gale svar. Les spørsmålene nøye og forsøk å beskrive det som passer best for deg. Noen spørsmål ligner på hverandre. Årsaken til dette er at spørreskjemaet er sammensatt av flere standardiserte spørreskjema brukt i forskning internasjonalt, og som ikke kan endres på. Det er derfor viktig at du besvarer alle spørsmålene om ikke annet er spesifisert.

Oppgi dag og måned for utfylling av skjemaet:// 2015	For neisepersoneii
Kjønn: Mann 🗌 Kvinne 🗌	ID-NR:
Hvem fyller ut skjema: Pasient selv 🗌 Pårørende 🔲	ICD-10/ICPC:
Din sykdom eller skade	
Hvilken type sykdom eller skade gjør at du henvises til/er på denne rehabilit	eringsinstitusjonen?
(Du kan sette flere kryss)	
Sykdom i muskel-skjelettsystem (f.eks. revmatisk sykdom, vonde mus eller bekkenplager	kler eller ledd, rygg-
Hjerte- og karsykdom (f.eks. hjerteinfarkt, hjertesvikt , angina)	
Hjerneslag	
Skade som skyldes fall, ulykke eller lignende	
☐ Kreft	
Psykisk lidelse	
Sykdom i nervesystemet (f.eks. Parkinsons, epilepsi, multippel skleros	e/MS)
Sykdom i luftveiene (f.eks. astma, KOLS)	
Stoffskiftesykdom/overvekt (f.eks. diabetes, sykdom i skjoldbruskkjert	elen/thyreoidea)
Amputasjon	
Leddprotese (hofteprotese/kneprotese e.l.)	
Annet: (Skriv her)	
Hvem søkte rehabiliteringsopphold for deg?	
Fastlegen Sykehus NAV	Andre

Har du vært opere	ert i løpet av de sis	te 4 ukene?	)			
Nei						
☐ Ja →	Hvis ja, da	to for siste	operasjo	n		
Av de siste 4 uken	e, hvor mange uk	er har du va	ært hjem	me?		
0	1		2	3		4
Hyordan vil du ara	dara da amartana	du bar batt	i lanot =	vy don sisto uko	(Cott ring run	dt att tall)
Hvordan vil du gra	2 3	4	5 5	6 7	8. (Sett ring run	9 10
Ingen smerter	2 3	4	5	0 /		så vondt som
					de	et går an å ha
				2 (2		
Har du, eller har d			sse plage	ene? (Sett et kry	yss per diagnos	
Hjerteinfarkt	J;	a Nei	Psor	iasis		Ja Nei
Angina pectoris (h	_			lgikt (reumatoio		
Hjertesvikt				psi	-	
Annen hjertesykdo	om [			iterews sykdom		
Hjerneslag/hjerne	blødning		Kreft	tsykdom		
Astma			Sark	oidose		🔲 🔲
Kronisk bronkitt, e	emfysem,			iske plager som		
KOLS Diabetes (sukkers		-		o for omyalgi		
Nyresykdom	_			sjegikt		
Eksem på hendene	_			skjørhet (osteo		
						<u> </u>
Huandan vil du bac	alcuiva din Evaialca E	2 /Cath	ah lemeaa\			
Hvordan vil du bes Meget god	God	-	et kryss) iddels	Dårli	a Me	get dårlig
		1411			g Mc	
Med mosjon mer	ner vi at du f.eks	. går tur, g	jår på sl	ki, svømmer e	ller driver tre	ning/idrett.
Hvor ofte driver du						
Aldri						
Sjeldnere enn en g						
En gang i uka						
2-3 ganger i uka Omtrent hver dag.			_			
omercia liver day.						
Dersom du driver	elik moeion eg oft	e som en o	ller flere	ganger i ukas h	vor hardt meei	onerer du?
(Sett et kryss)	onk mosjon, sa on	e som en e	ner nere	ganger ruka; n	voi marut mosj	onerer du?
Tar det rolig uten	å bli andpusten ell	er svett				
Tar det så hardt a	t jeg blir andpuste	n og svett				
Tar meg nesten he	elt ut					

Hvor lenge holder du på hver gang? (Sett	et kry	rss)					
Mindre enn 15 minutter							
15-29 minutter							
30 minutter – 1 time							
Mer enn 1 time							
Røyker du? (Sett et kryss)							
Nei, jeg har aldri røykt							
Nei, men jeg røykte tidligere							
Ja, sjeldnere enn en gang i uka							
Ja, hver uke	Antal	l sigare	etter hver uke				
Ja, hver dag	Antal	l sigare	etter hver dag				
De neste spørsmålene omhandler brui	ken a	v hole	satianecter de siste 12 måneder				
	ert i k	ontakt	med? (Sett et kryss pr.linje, og spesifiser				
hvis ja)							
	Ja	Nei	Hvis ja, omtrent hvor mange ganger				
Allmennlege/fastlege							
Legespesialist utenfor sykehus							
Legespesialist på sykehus							
Psykolog eller psykiater							
Fysioterapeut							
Ergoterapeut							
Kommunal pleie og omsorgstjeneste							
Har du siste 12 måneder vært innlagt på sykehus							
Har du siste 12 måneder vært innlagt på rehabiliteringsinstitusjon							
Har du siste 12 måneder vært innlagt på sykehjem							
Andre behandlere/alternative behandlere							
a							
b							
c							
d.							
<del></del>							

## Individuell plan

De som har behov for flere helsetjenester over lengre tid kan ha rett til «Individuell plan», hjemlet i Pasientrettighetsloven, som hjelp til et bedre samordnet helsetilbud.									
Kjenner du til «Individuell plan»?	Ja 🗌 N	lei 🗌							
Hvis ja, har det vært foreslått?	Ja 🗆 N	lei 🗌							
Har du «Individuell plan»?	Ja 🗌 N	lei 🗌							
Vi er interessert i din erfaring med helsetjenester og helsepersonell du har vært i kontakt med de siste 12 månedene.  For hver påstand skal du krysse av det alternativet som best beskriver din mening. Det er ingen svar som er riktig eller feil. Det er din personlige mening og erfaring som teller. Hvis en gruppe påstander ikke er aktuelle for deg går du videre til neste gruppe med påstander.  De neste påstandene handler om din oppfatning av din fastlege. Hvis du ikke har hatt kontakt med fastlegen din de siste 12 månedene kan du fortsette på neste gruppe påstander.									
		Svært enig	Enig	Hverken enig eller uenig	Uenig	Svært uenig	Vet ikke		
Jeg kjenner fastlegen min godt									
Fastlegen min kjenner godt til min syk	ehistorie								
Fastlegen vet hva han/hun har gjort ved tidligere besøk									
Fastlegen har god kjennskap til familieforholdene mine									
Fastlegen kjenner godt til mine daglige	e gjøremål								
Fastlegen tar kontakt med meg dersor nødvendig, uten at jeg må be om det	n det er								
Fastlegen vet godt hva jeg mener er v behandlingen og oppfølgingen av min									
Fastlegen har tilstrekkelig kontakt med blir behandlet av annet helsepersonell	d meg når jeg								
De neste påstandene handler om din oppfatning av samarbeidet mellom helsepersonell i kommunen, som du har hatt kontakt med (for eksempel: fastleger, fysioterapeuter, ergoterapeuter, sykepleiere, logopeder). Hvis dette ikke er aktuelt for deg kan du fortsette på neste side.    Svært   Enig   Hverken   Uenig   Svært   Vet   uenig   ikke									
				eller uenig					
De ulike faggruppene i kommunen er i informasjon seg i mellom	inke til å dele								
De ulike faggruppene i kommunen sar									
Behandlingen og oppfølging fra de ulik henger godt sammen									
De ulike faggruppene er alltid orienter behandling og oppfølging	t om hverandres								

De neste påstandene handler om din oppfatning av din (viktigste) spesialist. Hvis du ikk
har hatt kontakt med en spesialist (på sykehuset, poliklinikken eller i privatpraksis) de siste 12
månedene kan du fortsette på neste gruppe med påstander.

	Svært enig	Enig	Hverken enig eller uenig	Uenig	Svært uenig	Vet ikke		
Jeg kjenner denne spesialisten godt								
Denne spesialisten kjenner godt til min sykehistorie								
Denne spesialisten vet alltid hva han/hun har gjort ved tidligere besøk								
Denne spesialisten har god kjennskap til familieforholdene mine								
Denne spesialisten kjenner godt til mine daglige gjøremål								
Denne spesialisten tar kontakt med meg hvis det er nødvendig, uten at jeg må be om det								
Denne spesialisten vet godt hva jeg mener er viktig i behandlingen og oppfølgingen av min sykdom								
Denne spesialisten har tilstrekkelig kontakt med meg når jeg blir behandlet av annet helsepersonell								
eksempel mellom spesialist og annen spesialist, sy sykehuset). Hvis dette ikke er aktuelt for deg kan du fo			te gruppe Hverken enig					
	enig		eller uenig		derlig	IKKE		
Disse faggruppene er flinke til å dele informasjon seg i mellom								
Disse faggruppene samarbeider godt								
Behandlingen og oppfølgingen fra de ulike faggruppene henger godt sammen.								
De ulike faggruppene er alltid orientert om hverandres behandling og oppfølging								
De neste påstandene handler om din oppfatning av samarbeidet mellom din fastlege og spesialisten. Hvis dette ikke er aktuelt for deg fortsetter du på neste side.    Svært   Enig   Hverken   Uenig   Svært   Vet								
	enig	Ling	enig eller uenig	cerng	uenig	ikke		
Fastlegen og spesialisten er flinke til å dele informasjon seg i mellom								
Fastlegen og spesialisten samarbeider godt								
Behandlingen fra fastlegen og spesialisten henger godt sammen								
Fastlegen og spesialisten er alltid orientert om hverandres behandling og oppfølging								

#### De neste spørsmålene handler om vanskeligheter du har på grunn av din helsetilstand.

Helsetilstand omfatter sykdommer, andre kortvarige eller langvarige helseproblemer, skader, mentale eller følelsesmessige problemer, og problemer med alkohol eller narkotika.

Tenk tilbake på de siste 4 ukene, og svar på disse spørsmålene om mye vanskeligheter du har hatt med å gjøre følgende aktiviteter. For hvert spørsmål, vennligst sett ring rundt kun <u>ett</u> svar.

I løpet av de siste <u>4 ukene</u> , hvor store <u>vanskeligheter</u> har du hatt med:					
<u>Forståelse og kommunikasjon</u>					
<u>Å konsentrere</u> deg om å gjøre noe i <u>ti minutter</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å huske å gjøre <u>viktige</u> ting?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å analysere og finne løsninger</u> på problemer i dagliglivet?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å lære noe nytt,</u> f.eks. hvordan å komme fram til et nytt sted?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å stort sett forstå hva andre sier?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å starte</u> en samtale og <u>holde den i gang</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å bevege deg rundt</u>					
<u>Å stå oppreist over lengre tid</u> , slik som i 30 minutter?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å reise deg opp</u> fra sittende stilling?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å komme deg rundt i ditt eget hjem?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å komme deg ut</u> av ditt eget <u>hjem</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å gå en lengre strekning</u> , slik som én <u>kilometer</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Egenomsorg</u>			•	•	
<u>Å vaske deg</u> over <u>hele kroppen</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å kle på</u> deg?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å spise selv</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å være <u>alene</u> noen <u>få dager</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Samvær med andre</u>					
<u>Å ha</u> med personer <u>å gjøre som du ikke kjenner</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å pleie vennskap</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å komme overens</u> med personer som står deg <u>nær</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Å få nye venner</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Seksuelle aktiviteter?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
<u>Hverdagsaktiviteter</u>					
Å ivareta de <u>oppgavene</u> du har <u>ansvar for i</u> <u>husholdningen</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å gjøre de viktigste oppgavene i husholdningen <u>godt</u> <u>nok</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å få gjort alt det husarbeidet som du trengte å gjøre?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Å få gjort husarbeidet ditt <u>raskt nok</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke

Hvis du arbeider (lønnet, ulønnet, selvstendig) eller er under utdannelse, besvar de 4 neste spørsmålene. Hvis ikke, fortsett fra spørsmålene **Deltakelse i samfunnet**.

I løpet av de siste <u>4 ukene</u> , hvor store <u>vanskeligheter</u> har du hatt med:							
Ditt daglige <u>arbeid eller skoleqanq</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke		
Å gjøre de viktigste arbeids- eller skoleoppgavene dine <u>bra nok</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke		
Å få <u>gjort</u> alt det arbeidet du trengte å gjøre?	Ingen	Litt	En del	Store	Svært store/ klarte ikke		
Å få gjort arbeidsoppgavene dine <u>raskt nok</u> ?	Ingen	Litt	En del	Store	Svært store/ klarte ikke		

Deltakelse i samfunnslivet					
I løpet av de siste <u>4 ukene</u> :					
Hvor store problemer har du hatt med å <u>delta i</u> <u>aktiviteter i lokalsamfunnet</u> (f.eks. på festlige tilstelninger eller andre aktiviteter)?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Hvor store problemer har du hatt på grunn av hindringer i omgivelsene dine?	Ingen	Litt	En del	Store	Svært store
Hvor store problemer har du hatt med å <u>leve på en</u> <u>verdig måte</u> på grunn av andres holdninger eller handlinger?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Hvor mye <u>tid</u> har <u>du</u> brukt på helsetilstanden din eller på følgene av den?	Ingen	Litt	En del	Mye	Svært mye
Hvor stor har den <u>følelsesmessige påvirkningen</u> av helsetilstanden vært for <u>deg</u> ?	Ingen	Litt	En del	Stor	Svært stor
Hvor stor har <u>belastningen</u> vært på din eller familiens <u>økonomi</u> på grunn av helsetilstanden din?	Ingen	Litt	En del	Stor	Svært stor
Hvor store problemer har <u>familien</u> din hatt på grunn av helsetilstanden din?	Ingen	Litt	En del	Store	Svært store
Hvor store problemer har du hatt med å gjøre ting på egenhånd for å slappe av eller hygge deg?	Ingen	Litt	En del	Store	Svært store/ klarte ikke
Totalt sett i de siste 4 ukene, <u>hvor mange dager</u> var disse vanskelighetene til stede?	Før opp	o antall o	lager: 		
I de siste 4 ukene, hvor mange dager var du fullstendig ute av stand til å utføre vanlige aktiviteter eller arbeid på grunn av noe ved helsetilstanden din?	Før opp antall dager:				
I de siste 4 ukene, uten å regne med de dagene du var fullstendig ute av stand, hvor mange <u>dager kuttet</u> <u>du ned på</u> eller <u>reduserte</u> dine vanlige aktiviteter eller arbeid på grunn av noe ved helsetilstanden din?	Før opp antall dager:				

WHODAS 2.0

#### De neste spørsmålene omhandler hvordan du ser på din egen helse (SF-36®)

Disse opplysningene vil hjelpe oss til å få vite hvordan du har det og hvordan du er i stand til å utføre dine daglige gjøremål.

Hvert spørsmål skal besvares ved å krysse av det alternativet som passer best for deg. Hvis du er usikker på hva du skal svare, vennligst svar så godt du kan.

Sto	rt sett, vil du si helsen din er:	(kry	ss av ett altern Utmerket Meget god God Ganske god Dårlig	ativ)				
side	(kryss av ett alternativ)  Sammenliknet med for ett år  siden, hvordan vil du si at helsen din stort sett er nå?  (kryss av ett alternativ)  Mye bedre nå enn for ett år siden  Chrystal Ditt bedre nå enn for ett år siden  Chrystal Ditt dårligere nå enn for ett år siden  Mye dårligere nå enn for ett år siden							
	neste spørsmålene handler om sen din slik at den begrenser de			se aktivitetene	e <u>nå</u> ? Hvis ja, h	vor mye?		
				Ja,	ett alternativ på <b>Ja,</b>	Nei,		
				begrenser meg mye	begrenser meg litt	begrenser meg ikke i det hele tatt		
a.	Anstrengende aktiviteter som å tunge gjenstander, delta i anst		•	П	П	П		
b.	Moderate aktiviteter som å flyti støvsuge, gå tur eller drive me	te et	bord,					
c.	Løfte eller bære en handlekurv							
d.	Gå opp trappen flere etasjer							
e.	Gå opp trappen en etasje							
f.	Bøye deg eller sitte på huk							
g.	Gå mer enn to kilometer							
h.	Gå noen hundre meter							
i.	Gå hundre meter							
j.	Vaske deg eller kle på deg							
	pet av <u>de siste 4 ukene</u> , har du e daglige gjøremål på grunn av		_	de problemer i	i ditt arbeid elle	r i andre av		
	· •			(Kryss	av ett alternativ <b>JA</b>	/ på hver linje) <b>NEI</b>		
a.	Har du redusert tiden du har bi aktiviteter?	rukt	på arbeidet ditt	eller andre				
b.	Har du utrettet mindre enn du	hado	le ønsket?					
	Har du vært hindret i visse type							
d.	Har du hatt vanskeligheter med andre aktiviteter (f.eks. fordi d							

I løpet av <u>de siste 4 ukene</u> , har d dine daglige gjøremål på grunn av deprimert eller engstelig)?		_					re av
			(	Kryss av	ett altern		er linje) <b>EI</b>
<ul><li>e. Har du redusert tiden du har andre aktiviteter?</li><li>f. Har du utrettet mindre enn du</li></ul>			tt eller	- [ [			 ] ]
<li>g. Har ikke arbeidet eller utført a som vanlig</li>	andre akt	iviteter like	e nøye	1			]
I løpet <u>de siste 4 ukene</u> , i hvilken grad har din fysiske helse eller følelsesmessige problemer hatt innvirkning på din vanlige sosiale omgang med familie, venner, naboer eller foreninger?	Ikk	del	,				
Hvor sterke kroppslige smerter har du hatt i løpet av <u>de siste 4</u> <u>ukene</u> ?	Ing Me Sv Mo Ste	av ett alter gen get svake ake iderate erke get sterke					
I løpet av <u>de siste 4 ukene</u> , hvor mye har smerter påvirket ditt vanlige arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)?	Ikl	del	-				
De neste spørsmålene handler on ukene. For hvert spørsmål, vennli hatt det. Hvor ofte i løpet av <u>de s</u>	igst velg o	det svaralt	ernativet				
		Hele tiden	Nesten	ett alteri Mye av tiden	nativ på h En del av tiden	ver linje) Litt av tiden	Ikke i det hele
a. Følt deg full av tiltakslyst							tatt
b. Følt deg veldig nervøs							
c. Vært så langt nede at ingenti kunnet muntre deg opp	ng har						
d. Følt deg rolig og harmonisk							
e. Hatt mye overskudd							

	Hele tiden	Nesten hele tiden	Mye av tiden	En del av tiden	Litt av tiden	Ikke i det hele tatt
g. Følt deg sliten						
h. Følt deg glad						
i. Følt deg trett						
I løpet av <u>de siste 4 ukene,</u> hvor He mye av tiden har din <u>fysiske</u> Ne helse eller <u>følelsesmessiq</u> En problemer påvirket din sosiale	av ett alter le tiden sten hele i del av tide t av tiden te i det he	tiden en				
Hvor RIKTIG eller GAL er hver av de følgen	de påstan			. 0.		
Påstander om din helse	Helt riktig	(Kryss av Delvi: riktig		t D	ver linje) <b>elvis</b> gal	Helt gal
a. Det virker som om jeg blir lettere syk enn andre						
b. Jeg er like frisk som de fleste jeg kjenner						
<ul> <li>Jeg forventer at helsen min vil bli dårligere</li> </ul>						
d. Helsen min er utmerket						
De neste spørsmålene omhandler hvor (Sett ett kryss for hvert spørsmål)	ledes du	føler deg	j (HADS)			
Jeg føler meg nervøs og urolig		Jeg gled	der meg fo de før	rtsatt o	ver tinge	ne slik
Mesteparten av tiden		A	vgjort like	-		
Mye av tiden		_	kke fullt så	-		
Fra tid til annen		=	are lite gr			
Ikke i det hele tatt			kke i det h	ele tatt		
Jeg har en urofølelse som om noe forferdelig vil skje		Jeg kan situasjo	le og se o	let mors	omme i	
Ja, og noe svært ille			ike mye n	som fø	ir	
☐ Ja, ikke så veldig ille			kke like m	ye nå so	m før	
Litt, bekymrer meg lite		□ A	vgjort ikk	e som fø	ir	
Ikke i det hele tatt			kke i det h	ele tatt		

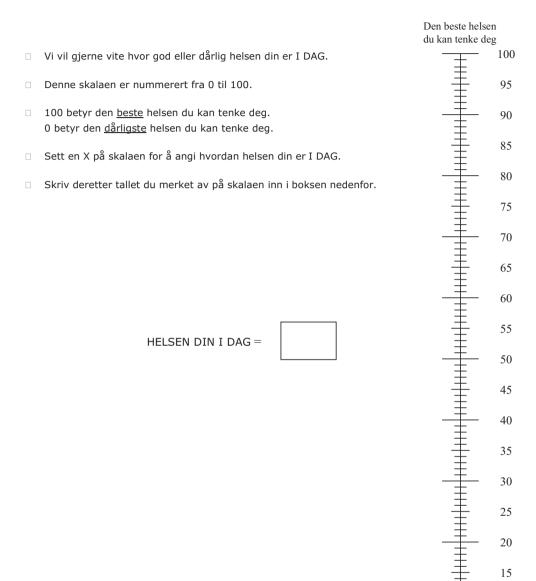
Jeg har hodet fullt av bekymringer	Jeg er i godt humør
Veldig ofte	Aldri
Ganske ofte	Noen ganger
Av og til	Ganske ofte
En gang i blant	For det meste
Jeg kan sitte i fred og ro og kjenne meg avslappet	Jeg føler meg som om alt går langsommere
Ja, helt klart	Nesten hele tiden
☐ Vanligvis	Svært ofte
☐ Ikke så ofte	Fra tid til annen
Ikke i det hele tatt	Ikke i det hele tatt
Jeg føler meg urolig som om jeg har sommerfugler i magen	Jeg bryr meg ikke lenger om hvordan jeg ser ut
Ikke i det hele tatt	Ja, jeg har sluttet å bry meg
Fra tid til annen	Ikke som jeg burde
Ganske ofte	Kan hende ikke nok
Svært ofte	Bryr meg som før
Jeg er rastløs som om jeg stadig må være aktiv	Jeg ser med glede frem til hendelser og ting
Uten tvil svært mye	Like mye som før
Ganske mye	Heller mindre enn før
☐ Ikke så veldig mye	Avgjort mindre enn før
☐ Ikke i det hele tatt	Nesten ikke i det hele tatt
[2]	
Jeg kan plutselig få følelse av panikk	Jeg kan glede meg over gode bøker, radio og tv
Uten tvil svært ofte	Ofte
Ganske ofte	Fra tid til annen
☐ Ikke så veldig ofte	☐ Ikke så ofte
☐ Ikke i det hele tatt	Svært sjelden
De følgende spørsmålene er knyttet til u	like sider av våre liv (SOC-13)
tallene 1 og 7 er de mest ytterliggående. Hvi	Sett kryss ved det tallet som uttrykker det du mener - s du ikke synes at svarene 1 eller 7 passer helt for
deg, sett kryss ved det tallet som best uttryk spørsmål.	ker dine følelser. Kun ett svar (kryss) på hvert
Føler du i bunn og grunn at du ikke bryr	deg om hva som skjer rundt deg?
Svært sjelden eller aldri	Svært ofte

Har det hendt a		rasket over h	vordan perso	ner som du	trodde du kje	nte
godt, oppførte s	seg?	3	☐ <sup>4</sup>	5	☐ <sup>6</sup>	O Alltid
						711110
Har det hendt a	t du ble skuff	et over perso	ner som du s	stolte på?	6	O 7 Alltid
Inntil nå har liv  1 Ingen klare mål e	2	3	4	□ <sup>5</sup>	□ <sup>6</sup> eget klare mål (	□ <sup>7</sup> og hensikt
Føler du at du b	olir urettferdig	behandlet?	<sup>4</sup>	5	☐ <sup>6</sup> Svært sjelden	7 eller aldri
Hvor ofte føler of 1  Svært ofte	du at du er i e	en uvant situa	sjon og at du	ikke vet h	<b>va du skal gjøi</b>	□ <sup>7</sup>
Å utføre dine da	2	3	4	□ <sup>5</sup> En kilde	☐ <sup>6</sup> til smerte og kj	□ <sup>7</sup> edsomhet
Har du svært m  1  Svært ofte	otstridende f	ølelser og tan	ker?	5	□ <sup>6</sup> Svært sjelden	oller aldri
Hender det at d  Svært ofte	u har følelser	inni deg som	du ikke øns	ker å ha?	□ <sup>6</sup> Svært sjelden	□ <sup>7</sup> eller aldri
Mange mennesi	ker, selv kara	ktersterke, fø	ler seg noen	ganger son	n tapere i visso	e
situasjoner. Hvo 1 Aldri	or ofte har du	følt det slik?	☐ <sup>4</sup>	5	6	□ <sup>7</sup> Svært ofte
Når noe har her  1  Overvurderte elle	2	3	4	5	□ <sup>6</sup> Du vurderte	☐ <sup>7</sup> det riktig
Hvor ofte føler of 1 Svært ofte	du at det er li	ten mening i	de tingene d	u gjør daglig	<b>g?</b>	□ <sup>7</sup> eller aldri
Hvor ofte har do	u følelser som	du ikke er si	kker på at du	u kan holde	under kontrol  6  Svært sjelden	☐ <sup>7</sup>

## Forventning etter rehabiliteringsoppholdet

	lan tror du helsen viliteringsoppholde		iknet med i dag, vil væ	re 6 måneder etter	
М	ye verre	Verre	Uforandret	Bedre	Mye bedre
Do ci	sta snørsmåland	ombandler	din helsetilstand (EQ	-ED-EL)	
	-			-	
Under	r hver overskrift b	er vi deg kryss	se av den ENE boksen s	som best beskriver	helsen din I DAG.
	GANGE				
<u> </u>	Jeg har ingen pr				
	Jeg har litt prob	_	_		
			er med å gå omkring		
	Jeg har store pr				
	Jeg er ute av sta	and til ă gă on	nkring		
PERS	ONLIG STELL	المسموسات	å vaske meg eller kle n		
$\vdash \vdash$					
			aske meg eller kle meg		
<u> </u>			er med å vaske meg el		
			å vaske meg eller kle m	neg	
	Jeg er ute av sta	and til å vaske	meg eller kle meg		
VANL			studier, husarbeid, fan å utføre mine vanlige g		riviteter)
H			a dtiøre mine vanlige gjør itføre mine vanlige gjør		
H			er med å utføre mine v		
			a utføre mine vanlige g		
	Jeg er ute av sta	and til a utrøre	mine vanlige gjøremål	l	
SMER	RTER / UBEHAG				
	Jeg har verken s	merter eller u	behag		
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-	Jeg har sterke s		=		
	Jeg har svært st				
	1 3				
ANGS	ST / DEPRESJON				
	Jeg er verken er	ngstelig eller d	eprimert		
	Jeg er litt engste	elig eller depri	mert		
	Jeg er middels e	ngstelig eller	deprimert		
	Jeg er svært en	gstelig eller de	primert		
	Jeg er ekstremt	engstelig ellei	deprimert		
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fortsett på siste side



Takk for at du svarte på alle spørsmålene!

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Den dårligste helsen du kan tenke deg

# **PAPER I**



# Validation of World Health Organization Assessment Schedule 2.0 in specialized somatic rehabilitation services in Norway

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#### Abstract

Purpose The World Health Organization Disability Assessment Schedule (WHODAS) 2.0 is a generic instrument to assess disability covering six domains. The purpose of this study was to investigate the potential of the instrument for monitoring disability in specialized somatic rehabilitation by testing reliability, construct validity and responsiveness of WHODAS 2.0, Norwegian version, among patients with various health conditions.

Methods For taxonomy, terminology and definitions, the Consensus-based Standards for the Selection of Health Measurement Instruments were followed. Reproducibility was investigated by the intra-class correlation coefficient (ICC) in a randomly selected sample. Internal consistency was assessed by Cronbach's alpha. Construct validity was evaluated by correlations between WHODAS 2.0 and the Medical Outcomes Study 36-item Short Form, and fit of the hypothesized structure using confirmatory factor analysis (CFA). Responsiveness was evaluated in another randomly selected sample by testing a priori formulated hypotheses.

Results Nine hundred seventy patients were included in the study. Reproducibility and responsiveness were evaluated in 53 and 104 patients, respectively. The ICC for the WHODAS 2.0 domains ranged from 0.63 to 0.84 and was 0.87 for total score. Cronbach's alpha for domains ranged from 0.75 to 0.94 and was 0.93 for total score. For construct validity, 6 of 12 expected correlations were confirmed and CFA did not achieve satisfactory fit indices. For responsiveness, 3 of 8 hypotheses were confirmed.

Conclusion The Norwegian version of WHODAS 2.0 showed moderate to satisfactory reliability and moderate validity in rehabilitation patients. However, the present study indicated possible limitations in terms of responsiveness.

**Keywords** WHODAS 2.0 · Disability · Rehabilitation · Reliability · Validity · Responsiveness

#### Background

One of three objectives of the World Health Organization (WHO) Disability Action Plan 2014–2021 is to strengthen the collection of relevant and internationally comparable data on disability [1]. Assessing disability is important for identifying needs when planning healthcare services, setting priorities, allocating resources and evaluating outcomes and effectiveness of interventions [1, 2]. Rehabilitation services target people with various health conditions and disabilities, and optimal functioning is the health goal.

The International Classification of Functioning (ICF), published in 2001, defines functioning and disability in a comprehensive perspective in terms of impairments, activity limitations and participation restrictions, in



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addition, personal and environmental factors [3]. After the release of ICF, WHO has put in an effort to develop a generic Disability Assessment Schedule (WHODAS) with their latest version 2.0 published in 2010.

WHODAS 2.0 and other instruments assessing disability are summarized in 'Rehabilitation Measures Database' [4]. While many instruments primarily focus upon function in primary activities like walking, eating, dressing and grooming, the WHODAS 2.0 also captures function in terms of different social participation activities. Reliable instruments assessing participation is advocated in rehabilitation studies [5, 6]. WHODAS 2.0 was cross-culturally developed and is exclusively based on the ICF component 'Activity and Participation' capturing self-perceived disability in six functioning domains defining disability as "a decrement in each functioning domain" [2]. The instrument can be used in general population, indicating a wide range of scores.

WHODAS 2.0 has been applied in surveys of different populations and patient groups using a 36-item version of the instrument, both in homogenous [7–13] and in heterogeneous groups of patients [14–18].

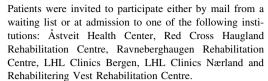
Though WHODAS 2.0 has been used in a wide range of health conditions, it has not been evaluated whether it can serve as a survey instrument for monitoring disability among all patients in specialized somatic rehabilitation services, including whether it is capable of assessing outcomes after rehabilitation. Since no generic instrument assessing disability among all rehabilitation patients has been tested in Norway, comparable data on disability are lacking. WHODAS 2.0 has been translated to Norwegian, and though consensus-based standard guidelines for translation have been followed [19], measurement properties have not been investigated for any health condition. Finally, the original hypothesized structure of the instrument has shown conflicting results in previous studies [14–16, 18].

The aim of the present study was therefore to examine the measurement properties of the Norwegian version of the 36-item version of WHODAS 2.0, as it provides most details, among a heterogeneous sample of patients accepted for specialized somatic rehabilitation. In addition to reliability and validity, responsiveness, which has been less investigated previously, was tested.

#### Methods

#### Design, setting and patients

The study was based on data from a cross-sectional study of patients from western Norway accepted for specialized somatic rehabilitation between January and June 2015.



Patients were included if they were at least 18 years old and had sufficient knowledge of the Norwegian language. An informed and written consent was obtained from all individual participants included in the study.

First, all patients completed a set of survey instruments including WHODAS 2.0 and the Medical Outcomes Study 36-item Short Form Health Survey version 1 (SF-36).

Second, to explore the reproducibility of the instrument, a randomly selected sample of patients from the waiting list completed WHODAS 2.0 a second time, within 15 days after first time of completion of WHODAS 2.0 and before admission at rehabilitation institution. Self-perceived change in health status between the two tests was assessed on a five-point Likert scale ranging from much worse to much better.

Third, in order to investigate the responsiveness of the instrument, another random sample of patients recruited at admission, completed WHODAS 2.0 a second time, 4–13 weeks after discharge from the rehabilitation institution. A single global question exploring self-perceived change of activities of daily living, including social participation, after rehabilitation compared to before rehabilitation, was assessed on a five-point Likert scale ranging from much worse to much better.

For taxonomy, terminology and definitions, Consensusbased Standards for the Selection of Health Measurement Instruments (COSMIN) were followed [20].

The study was approved by the regional ethical committee in western Norway, 2014-1636.

#### Instruments administered

WHODAS 2.0 is a generic patient-reported instrument that measures health and disability [2]. WHODAS 2.0 exists in a 36-item version and 12-item version with multiple versions with different options for administration [21]. In this study, the 36-item self-administered version was used which covers the following 6 domains: Cognition (6 items), Mobility (5 items), Self-care (4 items), Getting along (5 items), Life activities (8 items) and Participation (8 items) [22]. Life activities can be divided into activities relating to household (4 items) and activities relating to work/study (4 items). All questions relate to difficulties experienced during the previous 28 days (30 days in the original version). The scores assigned to each item are recoded and summed in each domain with a range from 0 (best) to 100 (worst), using complex scoring (SPSS algorithm is



available from WHO) [21]. For people working or studying, all 36 items are calculated to a total score; otherwise, 4 items are omitted. An algorithm enables calculation of domain score of *Life activities* and total score regardless of whether the 4 items relating to work/study are answered.

SF-36 version 1 is a generic patient-reported health survey instrument [23]. The SF-36 comprises 36 questions (items) along eight domains of health: mental health (5 items), vitality (4 items), bodily pain (2 items), general health (5 items), social functioning (2 items), physical functioning (10 items), role limitation related to physical problems (4 items) and role limitation related to emotional problems (3 items). An additional item captures changes in general health over the past year. Twenty questions relate to experiences during the previous 28 days. The response scores for each domain are added, followed by a conversion to a score between 0 and 100 with higher scores indicating better health [23]. The measurement properties of the instrument have been tested extensively [24].

#### Statistical analysis

Multiple imputations for missing items were applied according to the WHODAS 2.0 manual [22]. If the rate of missing items was >50 % in WHODAS 2.0 domains or in the total score, data were excluded. Number of imputation sets = 5. Missing items in SF-36 were managed according to the SF-36 manual [23].

Feasibility was assessed by exploring missing items of WHODAS 2.0, and a critical rate of 10 % missing items was used [17]. Scores on WHODAS 2.0 and SF-36 were quantified by the per cent of patients scoring, respectively, the lowest possible or highest possible score in the separate domains and in the total score. Floor effect was defined if more than 15 % obtained the lowest possible score (best for WHODAS 2.0; worst for SF-36), ceiling effect if more than 15 % obtained highest possible score (worst for WHODAS 2.0; best for SF-36) [25].

For reproducibility, intra-class correlation coefficients (ICC), two-way mixed with absolute agreement, were calculated for domain scores and total score for patients reporting no change in health status. An ICC > 0.70 was regarded as acceptable [25]. Smallest detectable change (SDC) for domains and total score was estimated [25].

Internal consistency was estimated by Cronbach's alpha coefficient. A coefficient between 0.70 and 0.95 is considered satisfactory [25].

Construct validity was explored by testing hypotheses formulated in advance, comparing WHODAS 2.0 domains to SF-36 domains. Expected correlations between all domains of WHODAS 2.0 and SF-36 domains were defined by authors VPM and MK individually, and the overall agreement of the expected correlation was 72.9 %

(35 of 48 correlations). Hypotheses about twelve correlations were chosen for the analysis; the intervals for expected correlations were: <0.3, between 0.3 and 0.6, and >0.6. If fewer than three (25 %) of the hypotheses were rejected, construct validity of WHODAS 2.0 was considered high, and for moderate validity 25–50 % and for low validity, more than 50 % should be rejected [26]. Pearson's correlation coefficients were estimated.

In addition to comparing WHODAS 2.0 to SF-36, the structural validity was assessed by testing if data (without items concerning work and study) fitted the original hypothesized structure of WHODAS 2.0 with confirmatory factor analysis (CFA). Cut-off close to 0.95 or higher for comparative fit index (CFI), cut-off close to <0.06 or lower for root-mean-square error of approximation (RMSEA) and cut-off close to 0.08 or lower were used to define a satisfactory fit of model [27].

Responsiveness was explored by testing eight hypotheses formulated in advance with the same satisfactory cutoff as construct validity. Three hypotheses included groups of patients in which a change was assumed, expecting the instrument would capture this change when compared to a group of patients where no or small change would occur. Two hypotheses addressed the individual level in a group of patients, one comparing the total score after rehabilitation to before; the second referred to the domain that was assumed to have the greatest change. Furthermore, three hypotheses were based on expected correlations with SF-36 when assessing construct validity. Two of the eight hypotheses addressed those patients who had undergone surgical treatment during the last 4 weeks before admission to the rehabilitation institution, since these patients were expected to have an improvement regardless of rehabilitation.

To complement the method assessing responsiveness using a priori formulated hypotheses, overall change score, effect size (ES) and standardized response mean (SRM) were calculated for domains and total score of WHODAS 2.0 and SF-36 [28–30]. An ES of 0.2 is regarded as low, 0.5 as moderate and 0.8 as high [31].

SPSS for Windows version 22.0 (SPSS Inc., Chicago, IL, USA) was used [32] for all statistical analyses except for the confirmative factor analysis where RStudio 099.879 with Lavaan package 05-20 was used. A significance level of 0.05 was chosen in all statistical tests.

#### Results

After exclusion of 31 patients due to missing data in WHODAS 2.0, items completed <16, 970 patients were included in the study. Table 1 shows diagnoses according to the International Classification of Diseases version 10



Table 1 Distribution on age, sex and ICD-10 categories among included patients accepted for specialized somatic rehabilitation

	Total sample $(n = 970)$	Reproducibility sample $(n = 53)$	Responsiveness sample $(n = 104)$
	n (%)	n (%)	n (%)
Age, mean (SD)	57.8 (14.1)	59.2 (13.4)	59.2 (13.5)
Female	613 (63.2)	34 (64.2)	68 (65.4)
Type of health condition			
Diseases of the musculoskeletal system and connective tissue	455 (46.9)	31 (58.5)	37 (35.6)
Diseases of the circulatory system	185 (19.1)	9 (17.0)	23 (22.1)
Diseases of the nervous system	83 (8.6)	5 (9.4)	7 (6.7)
Neoplasms	50 (5.2)	3 (5.7)	8 (7.7)
Endocrine, nutritional and metabolic diseases	37 (3.8)		5 (4.8)
Diseases of the respiratory system	36 (3.7)	3 (5.7)	5 (4.8)
Injury, poisoning and certain other consequences of external causes	26 (2.7)		3 (2.9)
Diseases of the skin and subcutaneous tissue	24 (2.5)		3 (2.9)
Factors influencing health status and contact with health services	23 (2.4)		6 (5.8)
Mental and behavioural disorders	13 (1.3)	2 (3.8)	1 (1.0)
Other	38 (3.9)		6 (5.8)

ICD-10 International Classification of Diseases version 10, SD standard deviation

(ICD-10) categories of the patients, age and female percentage for the three samples: total, reproducibility and responsiveness. The largest proportional (61.5 %) was referred to rehabilitation from their general practitioner, 27.7 % from hospital and 4.8 % from other practitioners (missing = 5.9 %). Fourteen per cent had undergone surgical treatment during the last 4 weeks when completing WHODAS 2.0 the first time and 82.0 % reported some kind of pain. Most (98.4 %) of the questionnaires were completed by the patients themselves. For 452 patients, the 36-item version of WHODAS 2.0 was used, as all items in *Life activities* were completed, whereas for 518 patients the 32-item version was used.

Table 2 shows descriptive statistics, missing percentage and reliability coefficients of WHODAS 2.0 and SF-36.

The number of missing was below the critical rate (10 %) in all items of WHODAS 2.0, 0.3–5.5 %, except the item concerning sexual activity (10.4 %) and items concerning *Life activities work/study* (53.3–55.2 %). Considering that four items are excluded for those who do not work or study, missing items of the total score were 2.2 % and for *Life activities work/study* 0.2–3.8 %.

Ceiling effect was not present in any domains. Floor effect was present in *Cognition*, *Self-care* and *Getting along*, with the highest percentage in *Self-care* (53.7 %).

Fifty-three patients completed WHODAS 2.0 a second time reporting no change in health status between tests; test–retest period was 7–15 days with mean of 11.6. Missing were lower for retest compared to test, between 0 and 3.0 % for domains.

SDC for the different domains ranged from 22.8 to 35.8 and was 16.2 for the total score.

Table 3 presents the correlation between WHODAS 2.0 domains and SF-36 domains, including the expected correlations marked in 'bold'. The correlations were negative due to opposing best scores. Six out of twelve hypotheses were confirmed.

For the 32-item version of WHODAS 2.0, excluding items concerning work and study, the standardized parameter estimates and fit indices for the second-order 6-factor model are shown in Fig. 1.

One hundred four patients completed WHODAS 2.0 a second time. Mean duration between these assessments were 48.4 days, ranging from 4 to 13 weeks after discharge from the rehabilitation institution. Missing was lower compared to the first time of completion, between 0 and 3.5 % for domains. The result from the single global question (1 missing: n=103) was as follows: 10.7 % reported worse (combining 'Worse' and 'Slightly worse'), 35 % no change and 54.4 % better (combining 'Slightly better' and 'Better'). A percentage of 19.4 reported surgical treatment during the last 4 weeks before admission to the rehabilitation institution. Change score, ES and SRM for WHODAS 2.0 and SF-36 are presented in Fig. 2. All



Table 2 Distribution and reliability of the WHODAS 2.0 and the SF-36 for patients accepted for specialized rehabilitation in western Norway between January and June 2015

Domain	N	Mean (SD)	Observed range	Floor (0) score %	Ceiling (100) score %	Missing domain %	Cronbach's α	Test-retest ICC <sup>a</sup>
WHODAS 2.0 [from 0 (best) to 100 (worst)]								
Cognition	950	17.8 (18.8)	0-90.0	27.6	0.0	2.7	0.87	0.81
Mobility	962	33.8 (25.8)	0 - 100.0	13.8	0.7	1.5	0.85	0.84
Self-care	968	12.0 (17.6)	0 - 100.0	53.7	0.1	0.6	0.77	0.63
Getting along	966	24.8 (20.9)	0 - 100.0	17.2	0.1	2.7	0.75	0.79
Life activities	963	45.1 (27.3)	0 - 100.0	7.1	4.0	27.4	0.91	0.78
Life activities: household	963	44.8 (27.5)	0 - 100.0	10.0	4.9	0.8	0.87	0.78
Life activities: work/study	452	42.9 (31.8)	0 - 100.0	13.8	12.1	1.7	0.94	0.71 <sup>b</sup>
Participation	952	41.1 (20.6)	0 - 100.0	2.1	0.1	3.1	0.83	0.75
Total score	970	30.9 (16.2)	0-90.2	0.5	0.0	7.9	0.92	0.87
SF-36 [from 0 (worst) to 100 (best)]								
Mental health	957	66.4 (19.3)	0 - 100.0	0.2	1.4	2.0	0.85	
Vitality	965	33.4 (20.3)	0 - 100.0	5.8	0.3	2.1	0.82	
Bodily pain	965	40.4 (25.8)	0 - 100.0	6.7	5.9	1.0	0.88	
General health	945	48.6 (22.2)	0 - 100.0	0.7	0.4	2.8	0.76	
Social functioning	969	55.4 (28.0)	0 - 100.0	5.1	10.4	2.0	0.85	
Physical functioning	959	53.3 (25.5)	0-100.0	1.8	1.8	1.6	0.90	
Role physical	940	16.6 (29.4)	0 - 100.0	67.8	6.7	3.8	0.80	
Role emotional	930	44.1 (43.2)	0-100.0	41.1	31.9	4.5	0.85	

WHODAS World Health Organization Disability Assessment Schedule, SF-36 Medical Outcomes Study 36-item Short Form Health Survey, SD standard deviation, ICC intra-class correlation

Table 3 Construct validity as measured by Pearson's correlation<sup>a</sup> (*r*) for WHODAS 2.0 versus SF-36 for 970 patients accepted for specialized rehabilitation in western Norway between January and June 2015<sup>b</sup>

	WHODAS	WHODAS 2.0							
	Cognition	Mobility	Self-care	Getting along	Life activities	Participation			
SF-36									
Mental health	-0.475	-0.188	-0.184L	-0.476M	-0.324	-0.547			
Vitality	-0.392	-0.312	-0.175	-0.365	-0.440	-0.495			
Pain	-0.170	-0.507	-0.293	-0.156	-0.380M	-0.436L			
Physical functioning	-0.146L	-0.764H	-0.498	-0.110	-0.488	-0.432			
Role physical	-0.140	-0.298M	-0.167	-0.159L	0.417	-0.367			
Role emotional	-0.296	-0.153	-0.145	-0.265M	-0.254	-0.380			
Social functioning	-0.419	-0.440	-0.328L	-0.451	-0.542	-0.660M			
General health	-0.319L	-0.325	-0.222	-0.326	-0.333	-0.471			

WHODAS World Health Organization Disability Assessment Schedule, SF-36 Medical Outcomes Study 36-item Short Form Health Survey; L=r<0.3 expected; M=0.3 < r < 0.6 expected; H=r>0.6 expected

change scores were <SDC for their, respectively, domains or total score. Nonparametric tests were performed since the data, i.e. domain scores and total score before and after rehabilitation, were not normally distributed. Table 4 presents the hypotheses with the results; five of eight hypotheses were rejected.



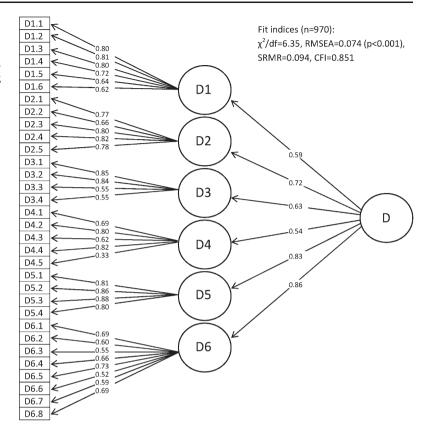
<sup>&</sup>lt;sup>a</sup> For test-retest, there were 53 patients analysed in the study

<sup>&</sup>lt;sup>b</sup> For Life activities: work/study, there were 21 patients analysed for ICC

<sup>&</sup>lt;sup>a</sup> All correlations had p < 0.001

b A priori formulated hypotheses marked in bold

Fig. 1 Standardized parameter estimates from confirmatory factor analysis: second-order 6-factor model. D1, cognition; D2, mobility; D3, self-care; D4, getting along; D5, life activities; D6, participation; D, total score/disability



#### Discussion

Numerous instruments can be used to assess disability and other health concepts in patients. However, WHODAS 2.0 captures functioning in activities and social participation using the ICF, which is internationally acknowledged, as the conceptual framework. In this study, the measurement properties of WHODAS 2.0, Norwegian version, have been tested to evaluate its potential as an instrument monitoring disability in somatic rehabilitation setting.

Most important, the study supported the results from previous studies of WHODAS 2.0 found in different language versions and populations with moderate to satisfactory reliability, moderate validity and low responsiveness. Our results support the use of WHODAS 2.0 in rehabilitation; however, some considerations should be taken when evaluating outcomes with the instrument.

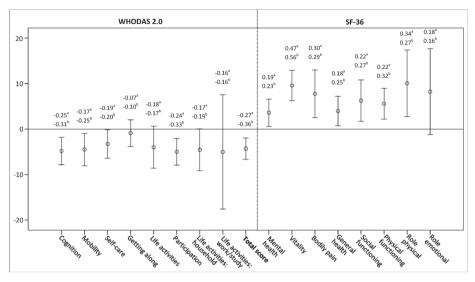
The Cronbach's alpha was all above 0.7 indicating satisfactory internal consistency which is consistent with other studies including similar groups of patients [9–12, 17, 18, 33, 34]. The ICC of the different domains

and for the total score indicated acceptable reproducibility except for *Self-care*. Since ICC is strongly influenced by the variance, low variability in this domain is indicated. In other studies, the reproducibility has been reported with ICC between 0.62 and 0.97 [7, 9, 12, 16, 18]. Reaching the satisfactory cut-off of 0.7, for both Cronbach's alpha and ICC, supports the use of WHODAS 2.0 for group comparison. However, for individual comparison, including use in clinical practice, an ICC as high as 0.9 is required [35].

The overall low level of missing items indicated high feasibility of WHODAS 2.0. The missing rate above the critical rate of 10 % in the item concerning sexual activity has also been reported in other studies [17, 18]. The possible causes may be that the item is irrelevant for some, or that sexual activity is considered a private issue. The high missing rate in items concerning *Life activities work/study* is due to the fact that many patients had not been working or studying the last 4 weeks prior to completing WHODAS 2.0.

While ceiling effect in *Life activities work/study* has been reported previously in patients with chronic diseases





**Fig. 2** Mean and 95 % CI of overall change score of WHODAS 2.0 and SF-36, domains and total, for rehabilitation patients 4–13 weeks after discharge from a rehabilitation institution compared to

admission to the institution (n=104). Change scores are opposite due to opposite best scores. <sup>a</sup>Effect size, <sup>b</sup>standardized response mean

Table 4 A priori hypotheses for examining the responsiveness of the WHODAS 2.0 for 104 rehabilitation patients, statistical results and if confirmed

	Hypotheses	Results	Confirmed
1.	Patients reporting positive change in global question have higher negative change scores in WHODAS 2.0 total score compared to patients reporting no change	$Z = -0.99; p = 0.349^{a}$	No
2.	Patients reporting negative change in global question have higher positive change scores in WHODAS 2.0 total score compared to patients reporting no change	$Z = -0.67; p = 0.506^{a}$	No
3.	Patients reporting positive change in global question have lower WHODAS 2.0 total score after rehabilitation compared to WHODAS 2.0 total score before rehabilitation	$Z = -3.13; p = 0.002^{a}$	Yes
4.	Patients reporting positive change in global question have lowest $Z$ value and lowest $p$ value in <i>Mobility</i> compared to other domains of WHODAS 2.0 after rehabilitation	Cognition: $Z = -3.05$ ; $p = 0.002^{a}$	No
		Mobility: $Z = -2.11$ ; $p = 0.035^{a}$	
5.	Patients reported to have undergone surgical treatment during the last 4 weeks have higher negative change scores in WHODAS 2.0 <i>Mobility</i> compared to patients reported no operation	$Z = -2.08; p = 0.038^{a}$	Yes
6.	Patients reported to have undergone surgical treatment during the last 4 weeks: change in WHODAS <i>Mobility</i> correlates with change in SF-36 physical functioning, correlation lower than $-0.5$	R = -0.169; p = 0.496	No
7.	The correlation of change on WHODAS 2.0 <i>Mobility</i> on SF-36 physical functioning is at least 0.3 lower than the correlation of change on WHODAS 2.0 participation with SF-36 pain	<i>R</i> : −0.194 versus −0.394*	No
8.	The correlation of change on WHODAS 2.0 participation on SF-36 social functioning is at least 0.1 lower than the correlation of change on WHODAS 2.0 cognition on SF-36 physical functioning	<i>R</i> : −0.470* versus −0.125	Yes

WHODAS World Health Organization Disability Assessment Schedule, SF-36 Medical Outcomes Study 36-item Short Form Health Survey, R Pearson's correlation coefficient

[16], no such effect was found in this study, although *Life activities work/study* had the highest proportion of ceiling scores at 12.1, approaching the threshold of 15 %. Floor

effects, which have been reported in previous studies [9, 14, 16, 18], were present in three of six domains, implying problems with respect to differentiating patients



<sup>&</sup>lt;sup>a</sup> Two-tailed asymptotic p value from Mann–Whitney's U test

<sup>\*</sup> p < 0.01

with low grades of disability. The high floor effect in *Self-care* indicates a high degree of self-reliance in the study population as expected as this is an admission criterion for the largest proportion of patients to these institutions. The low percentage of ceiling and floor scores seen in total score and the domain *Participation*, and to some degree *Life activities*, supports the use of these scores in rehabilitation studies in heterogeneous patient populations.

Based on Pearson's correlations, the number of supported pre-defined hypotheses, the construct validity was considered to be moderate compared to SF-36. Moderate and strong correlations, both expected and not predefined, between the domains of WHODAS 2.0 and SF-36 have been reported previously [7, 8, 15-17]. A method which has been utilized in two studies [15, 17] is grouping the domains of the WHODAS 2.0 and SF-36 into ICF dimensions: "Impairment", "Activity" and "Participation". Low, moderate and high correlations between the domains of these instruments grouped into "Activity" or "Participation" have been reported in these studies. A supplementary analysis was conducted adopting this method with their cut-offs to data of the present study. It resulted in 9 low, 2 moderate and 1 high correlations from Table 3, indicating that the domains in these instruments measure different aspects of the ICF dimensions or other health concepts. The use of both instruments when assessing the health status of rehabilitation patients is recommended.

The CFA of a second-order 6-factor model did not reach a satisfactory fit, indicating some degree of misfit. The item concerning sexual activity has also been reported as the lowest parameter estimate in a previous study and the authors suggested a cultural problem [14]. We have no indication that this is a problem in our study sample. In an adjusted model of WHODAS 2.0, with exclusion of the item concerning sexual activity, the fit indices did not differ considerable (data not shown), suggesting retaining this item. The fit indices for a first-order 6-factor model of the 32 items were slightly closer to satisfactory cut-off (data not shown). The findings are somewhat consistent with other studies which have reported fit indices not reaching the proposed satisfactory cut-off used in this study [14, 16, 18], and one study suggested improvement of the structure relocating some items [16]. The lack of consistency with original developers of WHODAS 2.0 may indicate future investigation of the structure, as also a two higher-order factors structure with three domains each has been proposed in patients with depression and low back pain [15]. However, to compare data with other studies using WHODAS 2.0, the original structure should be retained.

The definition and assessment of responsiveness is debated [30]. To our knowledge, this is the first paper

evaluating responsiveness of WHODAS 2.0 by testing a priori hypotheses. Results from our study showed low responsiveness related to this study population and its time period. 4–13 weeks.

Though distribution-based methods have some limitations in terms of assessing responsiveness [36, 37], these are often used. The ES reported in the present study was similar and lower compared to previous studies [11, 15–17] which may be explained by shorter assessment period and assessing a heterogeneous group of patients in this study. Low responsiveness was present for Cognition, Participation and total score if ES is considered to reflect responsiveness. The ES in Getting along (-0.07) may indicate a limited impact of rehabilitation on this domain. Since the domains have varying degrees of relevance for different groups of patients, and considering rehabilitation focuses on the individual with individual goals, change scores of the domains between these patients vary as reported in a previous study [17]. However, as ES and SRM are the observed change, results from ES and SRM will not be accurate if responsiveness is considered as the ability of an instrument to detect change [36]. Nevertheless, the results from the present study may indicate low suitability of WHODAS 2.0 for measuring short time changes after discharge from a rehabilitation institution. In addition, the higher SDC compared to change scores found in this study indicates that measuring change with WHODAS 2.0 beyond measurement error might be difficult.

#### Strengths and limitations of this study

The large sample size is an important strength, data collected from a prospective study inviting all patients accepted for specialized rehabilitation in western Norway. The sample size of reproducibility was above the number (n = 50) recommended as a minimum [25], however, lower than some comparable studies [9, 16].

The heterogeneity of the study population was expected since rehabilitation targets various health conditions. However, one previous study found different correlations of WHODAS II and SF-36 between different health conditions when assessing construct validity [17], entailing difficulties when preparing a priori hypotheses among a heterogeneous population.

Several considerations must be taken into account when interpreting the result of responsiveness. *Mobility* was included in three of eight hypotheses as this domain was expected to improve greatest in most patients during the assessment period. This may have underestimated the responsiveness. Four hypotheses were based on the global question, and this question may be too comprehensive for evaluating change in domains of WHODAS 2.0. Further, the responsiveness was tested with data collected between



4 and 13 weeks after discharge from rehabilitation institutions. This range may be too wide for measuring short time changes and too early after discharge for measuring change in certain domains [17, 38]. Additional follow-up after 6–12 months would probably provide better information about responsiveness. Furthermore, assessing responsiveness in a more homogenous population might simplify the predefined hypotheses. Finally, since responsiveness is an aspect of validity, three of the hypotheses may be considered as an evaluation of discriminate validity between known groups.

The lack of objective data on work and study contributed to a high percentage of ceiling score in the four items concerning work and study. Some patients answered these items by mistake by not reading the instructions in WHODAS 2.0, giving a low score in all these items.

Generalization of the results is only possible considering the study population. Most patients accepted for specialized somatic rehabilitation in Norway are expected to eat and wash themselves, excluding more disabled patients. No information about cognitive function was collected, which may influence data in some patients. However, since patients were self-reliant, this is probably a small problem.

#### Conclusion

The Norwegian version of WHODAS 2.0 showed moderate to satisfactory reliability and moderate construct validity compared to SF-36. There is some degree of misfit in the structural model, and there may be some limitations concerning the responsiveness. Overall, for surveying disability in cross-sectional studies and collecting comparable data among patients in specialized somatic rehabilitation, WHODAS 2.0 could be a first choice, as the instrument is based on the ICF, is generic and is easy to administer with high feasibility. Moreover, as rehabilitation puts the patient in focus with individual goals, inclusion of patient-specific instruments might be needed when the effects of rehabilitation are measured. Future studies evaluating short- and long-term responsiveness are needed.

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#### Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures were in accordance with the ethical standards of the regional research committee and with the Declaration of Helsinki 1964 and its later amendments.

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# **PAPER II**

# **ERRATA**

Table 1: The correct value of the category variable 'multimorbidity' is 348 for 'no', not 3489 as printed.







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Data Availability Statement: There are legal restrictions on sharing the de-identified data set for this study. Data contain potentially identifying and sensitive patient information. The Regional Committees for Medical and Health Research Ethics (REC) has imposed them. The extradition of data must be approved by REC. Contact information to REC is post@helseforskning. etikkom.no (Enter 'REC West' in the email subject field).

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RESEARCH ARTICLE

# Dimensions and predictors of disability—A baseline study of patients entering somatic rehabilitation in secondary care

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#### **Abstract**

#### **Purpose**

The purpose of this study was to investigate disability among patients who were accepted for admission to a Norwegian rehabilitation center and to identify predictors of disability.

#### Materials and methods

In a cross-sectional study including 967 adult participants, the World Health Organization Disability Assessment Schedule version 2.0 36-item version was used for assessing overall and domain-specific disability as outcome variables. Patients completed the Hospital Anxiety and Depression Scale (HADS), EuroQoL EQ-5D-5L and questions about multi-morbidity, smoking and perceived physical fitness. Additionally, the main health condition, sociodemographic and environmental variables obtained from referrals and public registers were used as predictor variables. Descriptive statistics and linear regression analyses were performed.

#### Results

The mean (standard error) overall disability score was 30.0 (0.5), domain scores ranged from 11.9 to 44.7. Neurological diseases, multi-morbidity, low education, impaired physical fitness, pain, and higher HADS depressive score increased the overall disability score. A low HADS depressive score predicted a lower disability score in all domains.

#### **Conclusions**

A moderate overall disability score was found among patients accepted for admission to a rehabilitation center but "life activities" and "participation in society" had the highest domain scores. This should be taken into account when rehabilitation strategies are developed.



**Competing interests:** The authors have declared that no competing interests exist.

#### Introduction

Disability is a complex phenomenon affecting many aspects of an individual's life, including common daily activities and participation in society, and it affects the individual's quality of life. Prevalence figures for disability vary. In 2011, the World Health Organization (WHO) estimated that 15% of the world's population lives with some form of disability and that this prevalence is increasing [1]. A precise definition of the concept of disability is lacking. The model of disability in the International Classification of Functioning, Disability and Health (ICF) [2] emphasizes the complexity, showing multifactorial determinants, including the interaction between health conditions and contextual factors with effects on impairment, activities, and participation in society.

The prevalence of disability increases with age  $[\underline{3}-\underline{5}]$ . Women report more functional limitations and a higher degree of disability compared with men  $[\underline{6}-\underline{1}1]$ . Additionally, an association between disability and marital status has been reported  $[\underline{1}2]$ . Higher educational level leads to better outcomes  $[\underline{7},\underline{1}2]$ , and living in rural areas is associated with higher disability compared with living in urban areas  $[\underline{1}3]$ . Poorer health and higher distress cause higher disability (i.e., multi-morbidity, impaired physical health, pain, and depressive symptoms)  $[\underline{7},\underline{1}3-\underline{1}5]$ . For symptoms of anxiety, the association with disability is not conclusive  $[\underline{7},\underline{1}6]$ .

Although the ICF was released in 2001, many of the above-mentioned studies conceptualize disability according to the medical model. Instruments that were developed from the 1970s and later, such as the Katz Index of Activities of Daily Living (1970) [17] and the Hospital Assessment Questionnaire (1980) [18], are still in use. Primary daily activities are often assessed in the concept of disability, while items concerning participation in society are seldom included in surveys [19]. The choice of model constituting the basis of a study is essential when investigating predictor variables because variables vary with disability domains [11].

The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) is based on the ICF model and was developed through a comprehensive process [20]. This instrument consists of an overall score and scores on the following dimensions: Cognition, Mobility, Self-care, Getting along, Life activities, and Participation in society. The WHODAS 2.0 has been translated into many languages, including Norwegian, and has been validated in various settings and countries, including specialized somatic rehabilitation [21].

Few studies have been conducted to assess determinants of disability conceptualized in the ICF among patients who are accepted for rehabilitation, even in secondary care. One previous study including people who applied to a disability registration system, investigated sociode-mographic/socioeconomic variables and the type and severity of impairment as predictors for disability [22]. The investigated group was eligible for disability benefits, but it is not clear whether the individuals in the study sample were accepted for rehabilitation, and people with musculoskeletal disorders, which is a large group in rehabilitation settings, were not included. Knowledge of determinants that are associated with disability is important for identifying subgroups for implementing preventive and treatment strategies [1, 3, 23], including rehabilitation settings.

In Norway, the Parliament has developed a national strategy for rehabilitation with the aim of providing disabled people with the tools to regain optimal functioning, health, and wellbeing. Primary care provides rehabilitation in municipalities to patients where long-term follow-up and competence related to the local community are required, with focus on the elderly population. Secondary care provides rehabilitation to patients with complex health issues in hospitals and rehabilitation centers. The characteristics of this service are comprehensive inter-professional interventions with a high degree of competence, methodology and infrastructure. In hospitals, rehabilitation is secondary to medical treatment which is the primary



goal of admittance. Patients admitted to the rehabilitation centers should be stable after medical treatment. Access to the Norwegian rehabilitation centers occurs after assessment of a general practitioner's referral or after elective or emergency hospitalization is completed.

The present study aimed to provide new knowledge on this patient group, to improve rehabilitation services. The aim was to present the overall disability scores and domain scores among these patients. Furthermore, the study also investigated associations between the overall disability score as measured by the WHODAS 2.0 and its dimensions, and sociodemographic factors, multi-morbidity, medical condition (diagnosis), physical fitness, pain, and symptoms of depression and anxiety.

#### Materials and methods

# Design, sample, and procedure

The study used data from a cross-sectional study of patients living in the Western Norway Health Region who were accepted for admission to a rehabilitation center. Data were collected between January 2015 and July 2015 as a baseline for a prospective cohort study surveying patients before admittance and after discharge from a rehabilitation center. All referrals from primary care are treated by a regional assessment team. Referrals from hospitals are sent directly to the rehabilitation center.

The patients were invited by mail from a waiting list or at admittance in the following rehabilitation centers: Åstveit Health Center, Red Cross Haugland Rehabilitation Center, Ravneberghaugen Rehabilitation Center, LHL Clinics Bergen, LHL Clinics Nærland, and Rehabilitering Vest Rehabilitation Center. Patients were included if they were at least 18 years old and had sufficient knowledge of the Norwegian language to complete a questionnaire. Patients who were referred for a follow-up stay and those who were referred to rehabilitation because of morbid obesity were excluded.

Patient-reported data were collected. For invitations by mail, a reminder was sent after 1 month. For patients who were invited to participate in the study at a rehabilitation center, the questionnaires were completed within the first 2 days after admittance, with no reminders. The main health condition (ICD-10 chapters) leading to referral was collected from the medical records.

Individual data on educational attainment, municipality of residence, and civil status, which were retrieved from public registers, were linked to survey data by Statistics Norway based on each patient's written consent.

#### **Ethics**

The study was approved by the Regional Ethics Committee West in Norway (REK-No. 2014–1636). Informed and written consent was obtained from all participants in the study.

#### Instruments

The survey package consisted of the WHODAS 2.0 [20], the Hospital Anxiety and Depression Scale (HADS) [24], and the EuroQol EQ-5D-5L [25]. The patients were also asked about smoking, physical fitness, physical activity, coinciding chronic conditions, and health care use.

#### Outcome variables

The WHODAS 2.0 36-item version is a generic, patient-reported instrument that measures health and disability based on the ICF [26]. The Norwegian version of this instrument has been tested for its psychometric properties in rehabilitation services, with satisfactory



reliability and moderate validity [21]. This instrument assesses disability during the last 28 days (30 in the original) in six functional domains. These domains are Cognition (6 items), Mobility (5 items), Self-care (4 items), Getting along (5 items), Life activities (8 items), and Participation (8 items). Life activities consist of activities related to the household (4 items) and activities related to work or study (4 items). The patient scores each item on a 5-point Likert scale with two anchor responses of "none" and "extreme or cannot do". Scores for each domain and an overall disability score were calculated according to the manual using "complex scoring" [26], with range from 0 (no disability) to 100 (full disability). For people working or studying, all 36 items were calculated for an overall score. Otherwise, four items were omitted and 32 items were computed as an overall score. An algorithm enabled calculation of the domain score of Life activities and the total score, regardless of whether the four items related to work or study were answered. In this study, all of the domain scores and the overall score were used as outcome variables.

#### Predictor variables

Age was categorized by decades.

Health conditions were divided into musculoskeletal, circulatory, and neurological diseases, neoplasms, endocrine, nutritional, and metabolic diseases, respiratory diseases, injuries and external causes, factors influencing health status and contact with health services, mental and behavioral disorders and miscellaneous. Miscellaneous conditions were as follows: symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital malformations, deformations, and chromosomal abnormalities (n = 3); and certain infectious and parasitic diseases (n = 2). In regression analyses, health conditions with n < 50 were merged with the miscellaneous conditions into one category, "other".

Multi-morbidity was defined as two or more coinciding chronic diseases or conditions by the same individual [27]. In addition to the referral diagnoses, one or more of the following diseases were reported: heart attack, angina pectoris, heart failure, other heart disease, stroke/cerebral hemorrhage, kidney disease, asthma, chronic bronchitis/emphysema/chronic obstructive pulmonary disease, diabetes, cancer, epilepsy, rheumatoid arthritis, Bechterew's disease, sarcoidosis, osteoporosis, fibromyalgia, arthrosis, and psychological problems (which have been consulted for previously). Any case of missing data was defined as an absence of the disease in question.

Admission was dichotomized as initial (referred from primary care) or ongoing management (referred from hospital).

Marital status was dichotomized to married and not married. Educational attainment was categorized as primary school, high school, and college/university. Smoking status was dichotomized to current smoking or non-smoking. Living area was dichotomized to rural and urban with a cutoff of 20,000 inhabitants in the municipality.

Physical fitness was measured by a single question with two anchor responses of "very poor" and "very good". Three categories were chosen: poor (merging very poor and poor), moderate, and good (merging very good and good).

Pain/discomfort was assessed using the EQ-5D (-5L) [25]. This instrument consists of five questions and a health rating scale. The questions assess physical activities, psychological distress, and pain/discomfort. For pain/discomfort, the score ranges from no pain/discomfort to extreme pain/discomfort, with a total of five responses. This instrument has been tested extensively for its measurement properties, among others in chronic conditions [28].



Depression and anxiety scores were assessed using the HADS [24]. This instrument forms two subscales, depression (HADS-D) and anxiety (HADS-A), with seven questions each with responses being scored on a scale of 0–3. For each subscale, the score ranges from 0–21 (higher score for higher severity). Scores for patients with less than three missing questions per subscale were included, and scores were imputed based on the mean across each person's available responses in each subscale. The HADS performs well as a screening instrument in assessing the severity of symptoms in somatic patients [29], shows adequate measurement properties in terms of validity and reliability, and a two factor-structure model is supported [30].

### Statistical analysis

The mean/median and standard error (SE) of the WHODAS 2.0 overall score and scores of the six domains were estimated according to categories of the different predictors. For two-group comparisons we used the exact chi-square test for categorical variables and the Mann-Whitney test for continuous variables. Analysis of variance (ANOVA) with F-test was performed to investigate differences in disability scores in variables with more than two categories. Tukey's post hoc test was used for subgroup comparisons. The relative risk of pain/discomfort related to sex was calculated.

The overall disability score and score of the domains were analyzed separately as response variables in linear regression models with the following predictor variables: sex, age, health condition, multi-morbidity, marital status, education, smoking, living area, physical fitness, HADS-D score, and HADS-A score. The EQ-5D (pain/discomfort), HADS-D, and HADS-A scores were treated as continuous variables, and the other variables as categorical variables.

Linear regression was first performed with one predictor variable at a time, and then with all predictor variables included simultaneously. Interactions were tested between health conditions, multimorbidity and physical fitness. For domains, only adjusted results are presented. Results are reported as the estimated regression coefficient (b), the SE or 95% confidence interval (CI), and p value from the F-test.

Missing items were treated according to the WHODAS 2.0 manual by using multiple imputations [26]. WHODAS 2.0 data were excluded if the rate of missing items was > 50% in domains or in the total score. The number of imputation sets was five. The significance level was chosen as 0.05 throughout. IBM SPSS for Windows version 23.0 (IBM Corp., Armonk, NY) was used for all statistical analyses.

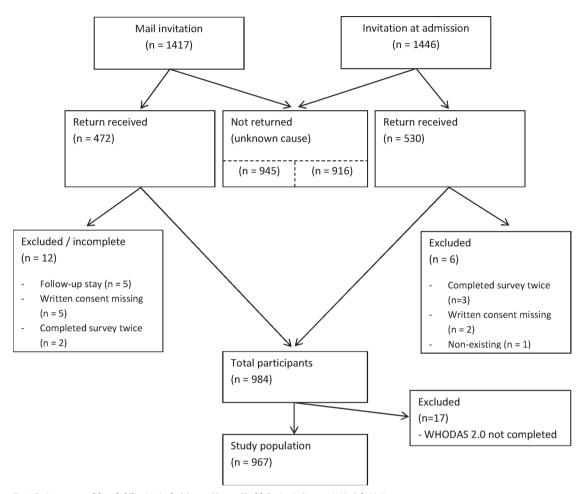
#### Results

A total of 3226 patients, living in the Western Norway Health Region, were accepted for admission to a rehabilitation center between January and July 2015, and 2863 were invited (1885 women and 978 men). Of these, 984 returned the questionnaire with signed consent and fulfilled the inclusion criteria, and 967 completed at least 50% of the items in the WHODAS 2.0. Therefore, the overall response rate was 34.6%, with 32.6% for women and 36.6% for men. Response rates for patients who were recruited per mail and at admission to rehabilitation centers were 32.7% and 36.8%, respectively. The lowest response rate was among those aged 18–29 years (17.7%) and > 80 years (20.7%), and the highest response rate was for patients aged 60–69 years (44.1%). Fig 1 shows details of the recruitment procedures.

# Characteristics of participants

The mean age (standard deviation: SD) of participants was 57.6 (14.0) years and 63.2% were women





 $\underline{\text{Fig 1. Patients accepted for rehabilitation in the Western Norway Health Region in January 2015} - \underline{\text{July 2015.}}$ 

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The mean/median HADS-D and HADS-A scores were 5.3/5.0 and 6.0/5.0, respectively, on a scale ranging from 0-21 (maximum distress).

Among the participants, 7.4% reported no pain/discomfort, 30.2% reported slight pain/discomfort, 33.4% reported moderate pain/discomfort, 24.2% reported severe pain/discomfort, and 4.7% reported extreme pain/discomfort. The female to male ratio was 1.37 for extreme pain/disability, 1.47 for severe pain/discomfort, 1.45 for moderate pain/discomfort, 0.63 for slight pain/discomfort and 0.39 for no pain/discomfort.

Women had a higher prevalence of multi-morbidity, a higher proportion of women were current smokers, fewer women were married, and women had a higher HADS-A-score compared with men (all p < 0.05).



A significantly higher proportion of non-participants (67.2%) was women compared with participants (63.2%), (p < 0.05). The mean age (SD) of non-participants, 55.6 (16.7) years, was significantly lower than that of participants, 57.6 (14.0) years, (p < 0.001).

There were larger proportions of women, musculoskeletal diseases, married, and smokers among patients with initial rehabilitation (all p-s<0.05), while there were more patients with circulatory diseases in the group of ongoing management (p<0.05).

### Missing data

The percentages of missing values were 0.9% for education, 5.8% admission, 0.3% for marital status, 1.9% for physical fitness, 4.1% for EQ-5D pain/discomfort, 1.2% for the HADS-D score, and 1.4% for the HADS-A score. The proportion of missing items for the WHODAS 2.0 ranged between 0.6% and 3.1% for the various domains, with the highest proportion of missing items in Participation and the lowest for Self-care. The item concerning sexual activity was missing for 10.3% of participants. The proportion of missing data for the other items ranged between 0.3% and 5.5%.

# Disability scores

<u>Table 1</u> shows the overall and domain disability scores according to the predictor variables. The mean (SE) overall disability score was 30.0 (0.5) and differed between the age groups (ANOVA p < 0.001). Patients aged from 40–49 years had the highest overall disability score, which was significantly higher than that of patients aged 50-59 and 60-69 years (p = 0.002and p = 0.001 respectively). The overall disability score differed also between the health conditions (ANOVA p < 0.001). Patients with neurological diseases reported the highest overall disability, which was significantly higher than that for respiratory diseases, factors influencing health status and contact with health services and circulatory diseases (p = 0.002, p < 0.001 and p < 0.001, respectively). Also, there were differences between the educational level groups (ANOVA p < 0.05). Patients with primary school education scored significantly higher on overall disability compared with those with secondary school and college/university education (p = 0.0034 and p = 0.002, respectively). However, there was no significant difference in overall disability between patients with secondary school and those with college/university education. Also for physical fitness there were significant differences (p < 0.001). Patients who reported good physical fitness had a significantly lower overall disability score compared with patients who reported poor or moderate physical fitness (p < 0.001 for both). And patients who reported moderate fitness had significantly lower overall disability score compared with patients who reported poor physical fitness (p < 0.001).

Mean scores for domains ranged between 11.9 and 44.7.

### Predictors for overall disability

Results from linear regression analysis for predicting the WHODAS 2.0 overall disability score are shown in Table 2. Except for living area, all predictor variables were significantly associated with disability in the unadjusted model (p < 0.05, i.e. men, initial rehabilitation, no smoking, being married, higher educational level, and better health significantly decreased the overall score). In the fully adjusted model, multi-morbidity, type of admission, education, physical fitness, the pain/discomfort item-score in EQ-5D, and the HADS-D score remained significant (all p < 0.05). Additionally, being referred with a neurological disease significantly increased the disability score compared with the other health conditions. No significant interactions were found, and the reported results are based on analyses with no interaction terms included in the statistical models.



Table 1. Distribution of overall and domain WHODAS 2.0 scores for disability<sup>a)</sup> for patients accepted for rehabilitation.

Disability		Overall score		Domain scores						
Variables		Fem		Cognition	Mobility	Self-care Getting		Life Partici		
Categories	n	Mean/median (SE)	(%)	Mean/median (SE)						
All	967	30.0/28.9 (0.5)	63.2	17.8/10.0 (0.6)	33.6/31.3 (0.8)	11.9/ 0.0 (0.6)	24.7/16.7 (0.7)	44.7/40.0 (0.9)	40.9/41.7 (0.7)	
Men	356	27.3/25.2 (0.8)	0.0	15.8/10.0 (0.9)	30.3/25.0 (1.4)	11.6/ 0.0 (0.9)	24.4/25.0 (1.1)	35.9/40.0 (1.5)	37.8/37.5 (1.1)	
Women	611	31.6/30.4 (0.6)	100.0	19.0/15.0 (0.8)	35.6/31.3 (1.0)	12.1/ 0.0 (0.7)	24.9/16.7 (0.9)	49.8/50.0 (1.1)	42.8/41.7 (0.8)	
age <sup>b)</sup> , years										
18-29	27	32.9/31.5 (3.3)	76.9	28.1/20.0 (5.2)	33.5/25.0 (5.5)	13.8/10.0 (4.3)	29.2/25.0 (4.8)	43.8/40.0 (4.9)	43.6/45.8 (3.9)	
30-39	79	32.7/30.5 (1.7)	86.1	21.3/20.0 (2.0)	30.6/31.3 (2.7)	12.5/ 0.0 (2.1)	25.9/25.0 (2.5)	51.9/50.0 (3.1)	47.8/45.8 (2.3)	
40-49	180	34.1/34.6 (1.2)	69.3	25.0/20.0 (1.5)	32.6/31.3 (1.8)	11.9/ 0.0 (1.3)	32.4/33.3 (1.9)	49.1/50.0 (1.9)	47.5/47.9 (1.5)	
50-59	246	28.5/28.3 (0.9)	58.8	17.1/10.0 (1.2)	29.7/25.0 (1.6)	9.5/ 0.0 (1.0)	23.5/16.7 (1.3)	43.4/40.0 (1.7)	41.0/41.7 (1.2)	
60-69	235	27.2/26.7 (0.9)	57.8	13.9/10.0 (1.0)	31.7/25.0 (1.8)	10.9/ 0.0 (1.2)	22.5/16.7 (1.2)	40.4/40.0 (1.8)	36.6/33.3 (1.4)	
70–79	154	29.6/28.3 (1.2)	57.4	13.4/ 5.0 (1.5)	41.8/43.8 (2.2)	15.6/10.0 (1.6)	21.3/16.7 (1.4)	44.9/40.0 (2.5)	35.9/33.3 (1.9)	
≥ 80	46	30.6/28.0 (2.2)	59.1	13.3/ 9.0 (2.7)	46.9/43.8 (4.0)	15.8/10.0 (3.0)	20.0/16.7 (2.5)	41.9/40.0 (4.6)	38.5/33.3 (3.2)	
Iealth condition, ICD-10				. ,						
Musculoskeletal diseases	454	33.2/32.3 (0.7)	75.3	19.2/15.0 (0.9)	40.1/37.5 (1.1)	13.7/10.0 (0.9)	26.0/16.7 (1.0)	50.8/50.0 (1.2)	44.9/41.7 (1.0)	
Circulatory diseases	185	22.9/20.0 (1.1)	33.3	13.8/10.0 (1.2)	19.7/12.5 (1.7)	9.5/ 0.0 (1.2)	20.5/16.7 (1.3)	31.4/30.0 (2.0)	32.3/29.2 (1.5)	
Neurological diseases	83	34.2/33.8 (1.6)	54.9	17.9/10.0 (2.1)	44.1/43.8 (2.9)	16.2/10.0 (2.1)	27.7/25.0 (2.4)	54.3/50.0 (3.0)	45.1/45.8 (2.2)	
Neoplasms	50	32.2/29.3 (2.1)	83.7	25.7/20.0 (3.2)	27.2/25.0 (3.3)	8.4/ 0.0 (1.8)	31.7/33.3 (3.4)	49.4/40.0 (3.5)	43.1/41.7 (2.9)	
Endocrine, nutritional, and metabolic diseases	36	26.4/26.9 (2.4)	80.6	19.5/15.0 (3.4)	25.0/25.0 (3.8)	10.3/ 0.0 (3.0)	21.6/20.8 (3.4)	37.1/40.0 (4.0)	35.9/41.7 (3.0)	
Respiratory diseases	36	22.6/22.7 (2.1)	52.8	10.7/ 5.0 (2.2)	25.6/21.9 (3.9)	3.4/ 0.0 (1.6)	19.9/16.7 (3.0)	33.2/30.0 (4.6)	33.2/33.3 (3.3)	
Injuries and external causes	26	33.5/32.8 (3.7)	69.2	14.8/ 5.5 (4.1)	48.6/53.1 (6.6)	19.2/10.0 (4.8)	21.2/16.7 (4.0)	52.0/60.0 (7.4)	42.8/39.6 (5.0)	
Skin diseases	24	26.9/24.2 (3.0)	70.8	14.2/ 7.5 (3.6)	33.6/31.3 (5.0)	10.4/0.0 (4.0)	22.8/20.0 (3.8)	35.9/40.0 (5.1)	38.0/33.3 (3.9)	
Factors influencing health status and contact with health services	23	19.4/16.9 (3.0)	30.4	13.7/10.0 (2.8)	9.4/ 6.3 (3.8)	4.8/ 0.0 (3.5)	23.8/16.7 (4.9)	26.4/25.0 (5.3)	27.5/25.0 (3.7)	
Mental and behavioural disorders	12	29.1/27.2 (2.9)	66.7	25.5/25.0 (4.7)	19.9/ 6.2 (7.4)	5.8/ 0.0 (2.9)	27.1/25.0 (5.3)	36.7/35.0 (6.3)	46.7/44.2 (3.6)	
Miscellaneous	38	30.1/30.3 (2.1)	55.3	19.0/15.0 (3.1)	33.0/31.3 (4.3)	9.6/ 0.0 (2.1)	26.8/25.0 (3.6)	41.4/40.0 (3.6)	42.0/41.7 (3.3)	
Multi-morbidity				` ,			`		<u> </u>	
Yes	619	32.0/31.1 (0.6)	65.6	19.7/15.0 (0.8)	35.5/31.3 (1.1)	13.8/10.0 (0.8)	26.7/25.0 (0.9)	47.5/50.0 (1.1)	43.1/41.7 (0.9)	

(Continued)



Table 1. (Continued)

Disability		Overall score	Domain scores							
Variables				Cognition	Mobility	Self-care	Getting along	Life activities	Participation	
Categories		Mean/median (SE)	(%)	Mean/median (SE)						
No	3489	26.5/25.0 (0.7)	58.5	14.3/10.0 (0.9)	30.1/31.3 (1.3)	8.5/ 0.0 (0.8)	21.1/16.7 (1.1)	39.7/40.0 (1.4)	37.1/37.5 (1.1)	
Admission										
Initial	644	32.0/31.1 (0.6)	65.6	19.2/15.0 (0.8)	33.3/31.3 (1.0)	11.0/ 0.0 (0.7)	26.5/25.0 (0.9)	45.7/50.0 (1.1)	42.6/41.7 (0.8)	
Ongoing management	267	26.5/25.0 (0.7)	58.5	13.8/10.0 (1.0)	32.5/25.0 (1.8)	13.2/ 0.0 (1.2)	20.0/16.7 (1.1)	41.2/40.0 (1.8)	35.8/33.3 (1.3)	
Marital status										
Not married	458	31.4/30.4 (0.7)	66.8	19.2/15.0 (0.9)	34.8/31.3 (1.3)	12.9/ 0.0 (0.9)	26.1/16.7 (1.1)	46.7/50.0 (1.3)	42.3/41.7 (1.0)	
Married	515	28.9/28.3 (0.7)	58.0	16.6/10.0 (0.8)	32.5/31.3 (1.1)	11.1/ 0.0 (0.7)	23.6/16.7 (0.9)	43.0/40.0 (1.2)	39.9/37.5 (0.9)	
Unknown	3	28.2/19.8 (8.3)	66.7	18.3/5.0 (14.4)	33.3/15.6 (16.7)	3.3/ 0.0 (3.3)	19.4/16.7 (8.2)	43.3/35.0 (10.9)	39.6/39.6(5.9)	
Educational level										
Primary school	198	32.9/32.2 (1.1)	68.8	21.4/15.0 (1.5)	39.5/38.8 (1.9)	14.5/10.0 (1.5)	25.4/16.7 (1.5)	46.6/40.0 (2.1)	44.1/41.7 (1.6)	
Secondary school	479	29.7/29.3 (0.7)	59.7	17.5/10.0 (0.9)	33.3/31.3 (1.2)	11.7/ 0.0 (0.8)	24.5/16.7 (1.0)	44.0/40.0 (1.3)	40.5/41.7 (1.0)	
College/university	277	28.2/26.1 (0.9)	66.1	15.4/10.0 (1.1)	29.7/25.0 (1.5)	10.2/ 0.0 (1.0)	24.9/25.0 (1.2)	44.3/40.0 (1.6)	39.1/37.5 (1.2)	
Unknown	9	34.4/35.9 (4.7)	38.5	23.0/10.0 (7.9)	37.0/31.3 (8.1)	16.9/ 0.0 (7.2)	23.1/16.7 (7.0)	47.7/40.0 (6.2)	48.1/45.8 (4.2)	
Smoking										
Yes	185	33.2/33.0 (1.0)	70.5	20.8/15.0 (1.4)	37.7/37.5 (1.9)	13.0/10.0 (1.2)	28.4/25.0 (1.6)	49.0/50.0 (2.0)	45.6/45.8 (1.4)	
No	773	29.3/27.4 (0.5)	65.7	17.1/10.0 (0.7)	32.5/31.3 (0.9)	11.6/ 0.0 (0.6)	23.8/16.7 (0.7)	43.7/40.0 (1.0)	39.8/37.5 (0.8)	
Living area										
Urban	508	30.5/29.3 (0.7)	65.0	17.8/10.0 (0.9)	34.6/31.3 (1.2)	12.6/ 0.0 (0.8)	24.8/16.7 (0.9)	46.5/50.0 (1.3)	41.4/41.7 (0.9)	
Rural	459	29.4/27.9 (0.7)	61.0	17.8/10.0 (0.9)	32.5/31.3 (1.2)	11.1/ 0.0 (0.8)	24.8/16.7 (1.0)	42.6/40.0 (1.3)	40.4/37.5 (1.0)	
Physical fitness										
Poor	413	35.3/34.5 (0.7)	64.9	21.4/15.0 (1.5)	42.6/43.8 (1.2)	15.6/10.0 (1.0)	29.1/25.0 (1.1)	53.0/50.0 (1.3)	47.2/45.8 (1.0)	
Moderate	375	27.9/26.1 (0.7)	63.7	17.5/10.0 (0.9)	29.1/25.0 (1.3)	9.5/ 7.4 (0.8)	22.8/16.7 (1.0)	41.1/40.0 (1.3)	39.0/37.5 (1.0)	
Good	163	21.3/18.7 (1.1)	56.1	15.4/10.0 (1.1)	20.7/12.5 (1.9)	8.1/ 0.0 (1.1)	18.0/13.3 (1.5)	31.0/30.0 (2.2)	29.9/29.2 (1.5)	
Unknown	18	28.5/20.3 (3.7)	72.2	13.8/10.0 (3.1)	31.9/21.9 (6.7)	8.3/ 0.0 (4.7)	25.5/25.0 (4.3)	48.8/50.0 (6.6)	36.3/33.3 (7.0)	

 $Abbreviations: \ WHODAS: \ World \ Health \ Organization \ Disability \ Score; \ ICD-1: International \ Classification \ of \ Diseases \ version \ 10; SE: \ standard \ error \ of \ the \ mean.$ 

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 $<sup>^{\</sup>mathrm{a})}$  All scores: 0 = lowest score of disability, 100 = highest score of disability.

b) Mean (standard deviation): 57.6 (14.0).



Table 2. Linear regression analysis for predicting WHODAS 2.0 overall scores for patients accepted for rehabilitation.

Predictor variable		Unadjusted models		Adjusted model			
Categories	b	95% CI	p value	b	95% CI	p value	
Intercept				1.37	(-2,32, 5.06)		
Female (ref: male)	4.32	(2.38, 6.27)	< 0.001	1.56	(-0.16, 3.29)	0.074	
Age, years			< 0.001			0.134	
18-29	5.70	(-0.25, 11.64)		2.33	(-2.56, 7.13)		
30-39	5.46	(1.71, 9.21)		0.03	(-3.13, 3.19)		
40-49	6.91	(4.04, 9.77)		1.98	(-0.40, 4.36)		
50-59	1.35	(-1.29, 3.98)		-0.85	(-2.98, 1.28)		
60-69	0.00	(Reference)		0.00	(Reference)		
70-79	2.44	(-0.59, 5.47)		0.59	(-1.92, 3.10)		
≥ 80	3.39	(-1.38, 8.16)		3.39	(-0.64, 7.42)		
Health condition			< 0.001			< 0.001	
Musculoskeletal diseases	10.30	(7.83, 12.76)		2.47	(0.03, 4.92)		
Circulatory diseases	0.00	(Reference)		0.00	(Reference)		
Neurological diseases	11.28	(7.57, 15.00)		5.62	(2.44, 8.80)		
Neoplasms	9.22	(4.73, 13.71)		4.37	(0.60, 8.14)		
Others <sup>a)</sup>	3.84	(0.95, 6.72)		-0.86	(-3.36, 1.64)		
Multi-morbidity (ref: no)	5.50	(3.55, 7.44)	< 0.001	2.35	(0.72, 3.99)	0.005	
Admission (ref: Initial)	-3,65	(-5.77, -1.52)	< 0.001	2.84	(1.02, 4.66)	0,002	
Unmarried (ref: married)	2.47	(0.58, 4.36)	0.011	-0.39	(-1.97, 1.19)	0.628	
Education			0.003			0.004	
Primary school	4.67	(1.94, 7.40)		3.66	(1.47, 5.84)		
Secondary school	1.52	(-0.68, 3.71)		1.27	(-0.50, 3.04)		
College/university	0.00	(Reference)		0.00	(Reference)		
Current smoking (ref: no smoking)	4.03	(1.64, 6.43)	0.001	-1.37	(-3.40, 0.67)	0.186	
Rural municipality (ref: urban)	-1.03	(-2.92, 0.86)	0.283	-0.70	(-2.23, 0.83)	0.369	
Physical fitness			< 0.001			< 0.001	
Poor	14.03	(11.47, 16.58)		5.60	(3.29, 7.90)		
Moderate	6.54	(3.95, 9.14)		2.71	(0.49, 4.94)		
Good	0.00	(Reference)		0.00	(Reference)		
EQ-5D (pain/discomfort) <sup>b)</sup>	5.89	(5.02, 15.52)	< 0.001	3.18	(2.28, 4.09)	< 0.001	
HADS-D score <sup>c)</sup>	2.17	(1.97, 2.36)	< 0.001	1.65	(1.39, 1.91)	< 0.001	
HADS-A score <sup>d)</sup>	-0.42	(-0.47, -0.38)	< 0.001	0.13	(-0.13, 0.38)	0.330	

Abbreviations: WHODAS: World Health Organization Disability Assessment Schedule; b: unstandardized estimated regression coefficient; CI: confidence interval; ref: reference; EQ-5D: EuroQol EQ-5D; HADS-D: Hospital Anxiety and Depression scale, depression subscale; HADS-A: Hospital Anxiety and Depression scale, anxiety subscale.

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a) Diseases included the following: endocrine, nutritional, and metabolic diseases (n = 37), respiratory diseases (n = 36), injuries and external causes (n = 26), factors influencing health status and contact with health services (n = 23), mental and behavioural disorders (n = 13), symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital malformations, deformations, and chromosomal abnormalities (n = 3); and certain infectious and parasitic diseases (n = 2).

 $<sup>^{\</sup>rm b)}$  From no pain/discomfort to extreme pain/discomfort, five categories.

 $<sup>^{\</sup>mathrm{c})}$  0 = lowest score of depressive symptoms, 21 = highest score of depressive symptoms.

d) All scores: 0 = lowest score of anxiety symptoms, 21 = highest score of anxiety symptoms.



#### Predictors for domain scores

Table 3 shows the results from multivariate regression analyses for predicting WHODAS 2.0 domain scores. Most health-related variables had an effect on domain scores, with better physical fitness and psychological health resulting in less disability. The exception was for Self-care where patients who reported a moderate physical fitness scored better than patients who reported a good physical fitness. Neurological diseases significantly increased the score on disability for most domains, except for Cognition and Getting along in which neoplasms significantly increased the score. The effect of the HADS-A score varied, with significantly increased scores in Cognition, Getting along, and Participation (p < 0.05), and significantly decreased scores in Mobility, and Life activities with an increase in the HADS-A score (p < 0.001); unstandardized estimated regression coefficients ranged from -1.07 to 0.63.

# **Discussion**

Rehabilitation patients have increased disability as a common characteristic. The mean overall WHODAS 2.0 disability score among patients who were accepted for admission to a rehabilitation center was 31.6 for women and 27.3 for men. In the normal non-institutionalized population in adults older than 18 years and in those living in private households, a score of 30 corresponds to the score for the 88th population percentile [26].

In the present study, disability scores for each domain varied considerably, and an important finding was that the highest disability scores among domains were found for Life activities and Participation. Although the WHODAS 2.0 may tend to favor a medical construct of disability [31], the items in Participation include explicitly contextual factors, which are seldom present in disability assessment instruments.

In our study, neurological disease, multi-morbidity, ongoing management, low educational attainment, impaired physical fitness, pain, and depressive symptoms significantly increased the overall disability score. Predictors of domain-specific disabilities varied with these variables, in addition to sex, age, urbanicity, and symptoms of anxiety. Marital status and smoking were the only variables that were not associated with any domain.

#### Strengths and limitations

This study has several important strengths. This is the first large cohort study in Norway among patients accepted for admission to a rehabilitation center, including nearly one thousand participants, representing the most common diagnoses that are found in the rehabilitation services. All patients from the western part of Norway, which includes 21.0% of the country's inhabitants [32], who were accepted for admission to a rehabilitation center within the first half of 2015, were invited to participate. The study was based on a large number of validated survey instruments and information from referral letters that was merged with data from public registers. There was a low number of missing values.

The main limitation is a relatively low response rate, probably due to the high number of items in the survey, leading to some selection bias. Although the response rate weakens the representativeness of the study sample and the external validity, the investigation of predictors relating to disability should be valid. The cross-sectional study design only presents associations and cannot explain the direction of causality. The external validity of findings is affected by the setting and dependent on Norwegian regulations determining the practice of rehabilitation in secondary care.



Table 3. Results of a fully adjusted multivariate linear regression analysis for predicting WHODAS 2.0 domain scores.

Predictor variable	Cognition		Mobility		Self-care		Getting along		Life activities		Participation	
Categories	b	(SE)	b	(SE)	b	(SE)	b (SE)		b (SE)		b	(SE)
Intercept	-4.03	(2.64)	-8.41	(3.66)	-4.63	(2.74)	5.60	(3.05)	1.94	(3.99)	6.89	(2.69)
Female (ref: male)	1.27	(1.23)	1.58	(1.71)	-1.04	(1.28)	-1.98	(1.42)	9.65	(1.86)**	1.47	(1.26)
Age, years		*		**				*				*
18-29	7.98	(3.44)	-2.60	(4.76)	1.65	(3.57)	3.59	(3.97)	-1.63	(5.20)	1.88	(3.50)
30-39	3.29	(2.25)	-9.77	(3.11)	-1.02	(2.34)	-1.36	(2.60)	3.16	(3.40)	3.07	(2.29)
40-49	5.66	(1.70)	-4.56	(2.36)	-1.23	(1.77)	5.73	(1.97)	1.50	(2.58)	3.69	(1.73)
50-59	1.28	(1.53)	-5.73	(2.12)	-2.72	(1.59)	-0.28	(1.77)	-0.03	(2.32)	0.36	(1.56)
60-69	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
70-79	-1.40	(1.86)	2.58	(2.27)	0.74	(1.94)	-1.32	(2.15)	-0.90	(2.82)	-3.20	(1.90)
≥ 80	-2.15	(3.22)	17.66	(4.46)	3.37	(3.35)	-1.97	(3.72)	1.37	(4.87)	-0.50	(3.28)
Health condition		*		**		*				**		
Musculoskeletal diseases	-0.90	(1.78)	9.51	(2.46)	0.60	(1.84)	-0.31	(2.05)	8.36	(2.68)	1.24	(1.81)
Circulatory diseases	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
Neurological diseases	0.74	(2.32)	15.95	(3.21)	4.37	(2.41)	2.71	(2.68)	13.17	(3.51)	4.49	(2.36)
Neoplasms	7.28	(2.67)	3.09	(3.69)	-1.84	(2.77)	6.78	(3.08)	8.73	(4.04)	3.45	(2.72)
Other <sup>a)</sup>	-1.96	(1.81)	3.01	(2.50)	-2.55	(1.88)	-1.26	(2.09)	-1.65	(2.73)	-0.97	(1.84)
Multi-morbidity (ref: no)	2.70	(1.17)*	1.37	(1.62)	3.31	(1.22)*	1.88	(1.36)	4.74	(1.77)*	2.49	(1.19)*
Admission (ref: Initial)	1.14	(1.32)	5.34	(1.82)*	4.67	(1.37)**	-0.21	(1.52)	5.13	(1.99)*	1.96	(1.34)
Unmarried (ref: married)	-0.96	(1.14)	0.67	(1.59)	0.42	(1.19)	-1.13	(1.32)	0.77	(1.73)	-1.04	(1.16)
Education		*		**								
Primary school	5.12	(1.57)	9.13	(2.17)	2.57	(1.63)	-1.43	(1.82)	1.49	(2.38)	3.62	(1.60)
Secondary school	2.36	(1.27)	2.85	(1.76)	1.39	(1.32)	-0.47	(1.47)	2.15	(1.93)	2.03	(1.30)
College/university	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
Current smoking (ref: no smoking)	-2.07	(1.46)	-1.28	(2.02)	-1.21	(1.52)	-0.44	(1.69)	-2.62	(2.21)	-2.01	(1.48)
Rural municipality (ref: urban)	0.03	(1.10)	-1.79	(1.53)	-1.03	(1.14)	0.01	(1.27)	-3.32	(1.67)*	-0.85	(1.12)
Physical fitness				**		**				**		**
Poor	0.92	(1.65)	12.62	(2.29)	2.37	(1.72)	0.93	(1.91)	10.20	(2.50)	5.25	(1.68)
Moderate	0.47	(1.59)	4.54	(2.21)	-0.62	(1.66)	-0.29	(1.84)	3.68	(2.41)	2.79	(1.62)
Good	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
EQ-5D (pain/discomfort)b)	0.42	(0.65)	7.32	(0.90)**	3.00	(0.68)**	1.24	(0.75)	4.53	(0.99)**	3.86	(0.66)**
HADS-D score <sup>c)</sup>	1.91	(0.19)**	1.26	(0.26)**	0.81	(0.19)**	2.26	(0.22)**	2.53	(0.28)**	2.13	(0.19)**
HADS-A score <sup>d)</sup>	0.65	(0.18)**	-0.76	(0.25)*	-0.12	(0.19)	0.57	(0.21)*	-0.96	(0.28)**	0.47	(0.19)*

Abbreviations: WHODAS: World Health Organization Disability Assessment Schedule; b: unstandardized estimated regression coefficient; SE: standard error; ref: reference; EQ-5D: EuroQol EQ-5D; HADS-D: Hospital Anxiety and Depression scale, depression subscale; HADS-A: Hospital Anxiety and Depression scale, anxiety subscale.

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a) Diseases included the following: endocrine, nutritional, and metabolic diseases (n = 37), respiratory diseases (n = 36), injuries and external causes (n = 26), factors influencing health status and contact with health services (n = 23), mental and behavioural disorders (n = 13), symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital malformations, deformations, and chromosomal abnormalities (n = 3); and certain infectious and parasitic diseases (n = 2).

b) From no pain/discomfort to extreme pain/discomfort, five categories.

 $<sup>^{\</sup>rm c)}$  0 = lowest score of depressive symptoms, 21 = highest score of depressive symptoms.

d) All scores: 0 = lowest score of anxiety symptoms, 21 = highest score of anxiety symptoms.

 $<sup>^{*}</sup>p \leq 0.05$ 

 $<sup>^{**}</sup>p \leq 0.001.$ 



# Possible explanations for the present findings and comparison with previous studies

The overall disability score as assessed by the WHODAS 2.0 of approximately 30 out of the maximum of 100, may be regarded as a relatively high functional level, considering 45 as the limit for substantial disability [33]. However, the present study showed higher overall disability scores than those previously found in similar studies [34, 35]. However, comparing absolute disability scores may be challenging because of contextual factors, including different health systems and time trends. The overall disability scores disguise larger domain-specific variations and the clinical utility of a sum score is questionable because various disability domains are included in this score. Consequently, the predictor variables are discussed and explained primarily in terms of domains.

In practice, criteria for admission to rehabilitation centers differ according to age. The requirements for older patients are stricter and a clear potential for improvement must be present, excluding the most disabled older people, both physically and cognitively. Consequently, increased disability with increasing age, which has been previously reported [3–5], was not found in the present study for the overall disability score. However, higher age was associated with higher disability for Mobility and lower disability for Cognition.

In our study, the score of Self-care, which assesses items addressing hygiene, dressing, eating, and staying alone, was especially low because most patients have to be able to care for themselves in the rehabilitation centers. In terms of some domain-specific disability scores, this contributes to a relatively homogenous study sample.

Despite the extended safety net of social welfare services in Norway aiming to enable participation in society, the score of Participation was high. The domain of Participation addresses contextual factors, including facilitation, others' attitudes and actions, and family and economic consequences of health conditions. These factors apply to various aspects of the social structure and are traditionally not targeted by health services. However, a more comprehensive understanding of this domain and the contextual factors influencing it, may contribute to improvement of interventions. This applies to all health conditions because scores in this domain were not associated with health conditions in the adjusted model in our study. The association between Participation and physical fitness may be related to physical barriers in society. A higher educational level has a universally positive effect on all forms of civic and social engagement [36], which may explain the lower scores in Participation.

In previous studies, women generally scored higher on disability  $[\underline{6}-\underline{11}]$ , which was not found in the present study. The only exception was higher scores in Life activities among women after adjustments, revealing problems concerning work and household. This probably reflects the traditional gender roles with less male responsibilities for the household  $[\underline{11}]$ .

In our study, the scores of disability varied between health conditions, which is in concordance with previous studies [11, 22, 37]. The scores for neurological diseases were especially high for domains mainly including physical components, Mobility and Life activities, which is consistent with a previous study [22]. An interesting finding in our study was the relation between neoplasms and high scores in the cognitive domains of Cognition and Getting along. Cognitive difficulties have been reported for patients after cancer treatment [38, 39] and should be taken into consideration when planning rehabilitation interventions for this group.

Multi-morbidity has been found to increase the level of disability [7, 13, 40], which was also found in the present study. However, there was no association between multi-morbidity and Mobility. This is in contrast to a previous study that assessed domain-specific associations [11], and in studies that only used instruments capturing mobility [13, 40]. One explanation for this discrepancy between our study and other studies may be the exclusion of the most



disabled patients with high multi-morbidity in Norwegian rehabilitation centers. While our study investigated multi-morbidity as a dichotomized variable, other studies used several categories [11] or used multi-morbidity as a continuous variable [7], where a gradual increase in disability with the number of chronic conditions was reported.

In rehabilitation programs, physical activities are often included to increase the health and function of patients [41]. A previous study on adults with arthritis [14] showed that better perceived physical health was associated with lower disability levels. With regard to overall disability, this finding is in accordance with our study. However, only scores for domains including physical components were associated with this variable. For domains with mainly cognitive components, Cognition and Getting along, no effect of perceived physical fitness was observed.

Higher pain increases the disability scores in people with arthritis [14], which is in agreement with findings in the present study. Although a reduction in pain is not usually considered as the primary goal of rehabilitation, a reduction in pain may be a secondary gain, intervening with cognitive and physical components. In this study, pain did not affect disability scores in the cognitive domains of Cognition and Getting along.

In our study, depressive symptoms significantly increased disability in all domains, which is consistent with studies that included disease-specific groups and older people [15, 40].

In the current study, no significant association between symptoms of anxiety and the overall disability score was found. However, more symptoms of anxiety increased disability in Cognition, Getting along, and Participation, but resulted in lower scores in Mobility, Self-care, and Life activities. The role of anxiety has been less investigated compared with depressive symptoms, but is associated with disability in older populations only in women [7]. Whether this finding reflects a significant association or merely a statistical artefact should be further investigated in larger population studies. A previous prospective cohort study showed that disability per se predicts future disability for older people [42]. This variable should be investigated further in a prospective study and a regression model for analysis of future disability in the present cohort is currently underway.

The WHODAS 2.0 does not assess all aspects of disability, and the results may not necessarily correlate with the specific disability for which for the patient is referred. However, we assume that the most important aspects of disability are included in the WHODAS 2.0 and are of significance for each patient.

#### Conclusion

The present study shows a relatively low overall disability level, which is probably explained by the fact that most patients must be able to care for themselves in the rehabilitation centers in the secondary care in Norway. Patients struggle most in Life activities and Participation, and this should be taken into account when future treatment strategies for rehabilitation services are developed. However, targeting these domains can also be done in primary care, probably even better, because of the competence related to the local community. Further research to identify determinants for disability should especially focus on participation restrictions to improve rehabilitation as a comprehensive process. Knowledge of and targeting determinants of disability may not only reduce disability levels, but could also improve other clinical outcomes, such as quality of life.

Referring patients with lower level of disability to primary care could allocate more resources for rehabilitation to patients with higher level of disability at the rehabilitation centers. However, the potential of improvement following rehabilitation as a criterion for admission must not be waived.



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# **PAPER III**

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1 Running head: 2 Coping resources and health 3 4 Title: Sense of Coherence, disability, and health-related quality of life: a cross-sectional study of 5 6 rehabilitation patients in Norway 7 Vegard Pihl Moen, M.Sc. <sup>1,2</sup>, Geir Egil Eide, Dr.Philos <sup>2,3</sup>, Jorunn Drageset, Ph.D.<sup>2</sup>, Sturla Gjesdal 8 Dr.Med. <sup>2</sup> 9 10 11 Affiliations: <sup>1</sup> Centre for Habilitation and Rehabilitation, Haukeland University Hospital, Bergen, Norway 12 <sup>2</sup> Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway 13 <sup>3</sup> Centre for Clinical Research, Haukeland University Hospital, Bergen, Norway 14 15 This study was performed at the Centre for Habilitation and Rehabilitation, Haukeland 16 University Hospital, Bergen, Norway 17 18 19 Acknowledgment: 20 We thank the World Health Organization for technical support in obtaining the WHODAS 2.0. Furthermore, we thank all rehabilitation institutions (Åstveit Health Center, Red Cross Haugland 21 22 Rehabilitation Centre, Ravneberghaugen Rehabilitation Centre, LHL Clinics Bergen, LHL Clinics 23 Nærland and Rehabilitering Vest Rehabilitation Centre) and participating staff for recruiting patients

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1 Sense of Coherence, disability, and health-related quality of life: a cross-sectional study 2 of rehabilitation patients in Norway 3 4 5 Abstract 6 **Objective:** To study relationships between Sense of Coherence (SOC), disability and mental 7 and physical components of health-related quality of life (HROoL) among rehabilitation 8 patients. 9 Design: Survey. **Setting:** Rehabilitation centers in secondary care. 10 Participants: A total of 975 from the Western Norway Health Region consented to 11 participate and had valid data of the main outcome measures. 12 13 **Interventions:** Not applicable 14 Main outcome measures: SOC was measured with the Sense of Coherence questionnaire (SOC-13), disability with the World Health Organization Disability Assessment Schedule 2.0 15 (WHODAS 2.0), and HRQoL with the Short Form health survey (SF-36). 16 17 Results: Mean scores (standard deviation) were 62.9 (12.3) for SOC-13, 30.8 (16.2) for WHODAS 2.0, 32.8 (9.6) for SF-36 physical component score and 43.6 (11.8) for SF-36 18 mental component score. Linear regression analysis showed that increased SOC score was 19 associated with reduced disability scores in the following domains with estimated regression 20 coefficients (95% confidence interval; CI) Cognition -0.20 (-0.32 to -0.08), Getting along 21 -0.36 (-0.52 to -0.25), and Participation -0.23 (-0.36 to -0.11). The fit of two structural 22

- models with the association from SOC to HRQoL and disability or with disability as a 1 mediator was better for the mental versus the physical component of HROoL. High SOC 2 increased the mental component of HRQoL, consistent for all diagnostic groups. For both 3 4 models, good fit was reported for circulatory and less good fit for musculoskeletal diseases. 5 **Conclusions:** The results indicate that higher SOC decreases disability in mental domains. The effect of SOC on disability and HRQoL might vary between diagnostic groups. SOC 6 7 could be a target in rehabilitation, especially among patients with circulatory diseases, but prospective studies are needed. 8 9 10 11 Key words: Health-related quality of life, Sense of Coherence, health status, rehabilitation 12 13 14 List of abbreviations: CI: confidence interval 15 16 EQ-5D-5L: EuroQol 5 dimensions 5 levels HRQoL: health-related quality of life 17
- 19 MCS: Mental Component score (of the SF-36)

ICF: International Classification of Functioning, Disability and Health

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20 PCS: Physical Component score (of the SF-36)

1	SEM: structural equational modeling
2	SF-36: Medical Outcomes Study Questionnaire Short Form 36 Version 1
3	SOC: sense of coherence
4	SOC-13: 13-item sense of coherence scale
5	WHODAS 2.0 = World Health Organization Disability Assessment Schedule version 2.0
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1 Rehabilitation aims to maintain or increase functional status and health-related quality of life

2 (HRQoL). <sup>1-3</sup> Rehabilitation patients usually have chronic conditions with sensory, cognitive,

3 and mobility impairments, and experience activity limitations as well as participation

4 restrictions. HRQoL is poorer in rehabilitation patients compared with a healthy reference

5 population. <sup>4</sup>

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Aron Antonovsky developed a "salutogenic" model to explain why some people remain

healthy, or even improve their health, when experiencing life events (stressors) whereas

others become ill. 5 A key concept in Antonovsky's model is Sense of Coherence (SOC), a

measure of an individual's capacity to cope. SOC captures an individual's perception of life

as being comprehensible, manageable, and meaningful. <sup>5</sup> Strong SOC indicates adaptive

strategies when responding to stressors <sup>6</sup> and results in better health, reduced risk of mortality,

and lower distress in terms of depression, anxiety and pain. <sup>7-12</sup> Therefore rehabilitation could

include goals that strengthen individuals' SOC. <sup>13</sup> Better knowledge of SOC and how it affects

disability and HRQoL may help to identify subgroups when planning rehabilitation and

tailoring interventions. 14

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Previous studies have shown that strong SOC is related to less disability. <sup>14-16</sup> One study reported that SOC was a protective factor for disability. <sup>14</sup> However, that study only included older adults and used an overall disability score, which may be less relevant in clinical settings than disability domains. To our knowledge, no previous studies have investigated the effect of SOC on disability (as conceptualized in the International Classification of

Functioning, Disability and Health; ICF <sup>17</sup>) among rehabilitation patients. Relationships

between SOC and disability domains such as participation in society have not been assessed.

2 Measurement of HROoL provides an evaluation of health encompassing many important aspects. 18 among others disability, and may be considered the ultimate outcome for health 3 care. <sup>19</sup> A comprehensive review has shown that better HROoL is associated with higher SOC 4 in various patient populations. <sup>20</sup> Moreover, a study among adolescents with congenital heart 5 disease showed a predominant direction of this association from SOC to perceived health, <sup>21</sup> 6 7 suggesting further investigation of this relationship and its direction in other populations. 8 9 We have not found any studies investigating the direction of the association from SOC to 10 HROoL and disability simultaneously, whether SOC has a direct relationship to HROoL and disability, or if the direction of the association from SOC to HROoL is mediated by disability 11 (Figure 1). 12 13 Figure 1 14 15 Multimorbidity and pain are associated with increased disability and poorer HROoL <sup>22-25</sup>: 16 moreover, multimorbidity impairs SOC. 8 Studies have also shown associations between 17 sociodemographics, psychological distress, and SOC, disability, and HRQoL. 26-28 18 19 This study aimed to increase the understanding of SOC, disability, and HRQoL in 20 rehabilitation patients. Specific objectives were to: 1) describe the simultaneous distribution 21

of SOC, disability, and HRQoL; 2) investigate possible effects of SOC on disability domains;

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1	and 3) investigate hypothesized structural models for SOC, disability, and HRQoL. Analyses
2	were also performed specifically for diagnostic groups to enhance clinical significance.
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5	Methods
6	Design, sample, and procedure
7	The study used a cross-sectional design. All patients in the Western Norway Health Region
8	accepted for inpatient or outpatient rehabilitation at a rehabilitation center in secondary care
9	during the first half of 2015, and who were referred from hospitals or general practitioners,
10	were invited by mail or at admittance. A flow chart showing participant inclusion and
11	exclusion is shown in Figure 2. Further details are provided in a previous paper. <sup>29</sup>
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13	Figure 2
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15	Patient-reported data were linked to individual public register data obtained from Statistics
16	Norway, on educational attainment, residence municipality, and marital status.
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18	Ethics
19	This study was approved by the Regional Committee for Medical Research Ethics in Western
20	Norway, REK-No. 2014-1636. Written informed consent, including linkage to public register
21	data, was obtained from study participants

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Main variables

3 The 36-item World Health Organization Disability Assessment Schedule version 2.0 (WHODAS 2.0) assesses disability across six domains <sup>30</sup>: Cognition (six items), Mobility 4 5 (five items), Self-care (four items), Getting along (five items), Life activities (eight items), 6 and Participation (eight items). Four Life activities items relate to household and four to work 7 or study. Responses are on a 5-point Likert scale with two anchor responses ("none" and "extreme or cannot do"). Domain scores and a total disability score are calculated using 8 "complex scoring" according to the manual; ranging from 0 (no disability) to 100 (full 9 disability). An algorithm enabled calculation of a score for the Life activities domain and a 10 total score (regardless of whether the four items related to work or study were answered). The 11 instrument has satisfactory reliability and moderate validity for use in rehabilitation services. 12 31 13 14 The Medical Outcomes Study Short Form Health Survey Version 1 (SF-36) assesses HRQoL. 15 <sup>32</sup> The scale contains 36 items in eight domains: Mental health, Vitality, Bodily pain, General 16 health, Social functioning, Physical functioning, Role limitation related to physical problems, 17 and Role limitation related to emotional problems. In addition, one item assesses changes in 18 general health over the past year. The eight domain scores can be summarized to give a 19 mental component score (MCS) and a physical component score (PCS), which were used in 20 this study. Scores range from 0 to 100, with higher scores indicating better HROoL. The 21 instrument is a valid measure of health status for a range of patients <sup>33</sup> with adequate and high 22 reliability. 34 23

- 1 The 13-item SOC scale (SOC-13) 35 comprises items in three subscales: comprehensibility,
- 2 manageability, and meaningfulness. Each item is scored on a 7-point Likert scale with two
- anchor responses ("never" and "very often"). After reversing five negatively formulated
- 4 items, all items are summed to give a total score of 13–91; higher scores indicate stronger
- 5 SOC. The SOC-13 has generally acceptable reliability and validity. <sup>36-38</sup>

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#### Adjustment variables

- 8 Symptoms of depression and anxiety were assessed using the Hospital Anxiety and
- 9 Depression Scale (HADS) <sup>39</sup> which comprises 14 items on two subscales: anxiety (HADS-A)
- and depression (HADS-D). Each subscale has seven items. Scores range from 0 to 21, higher
- 11 scores representing higher severity. HADS performs well as a screening instrument in
- 12 assessing symptom severity in somatic patients <sup>40</sup> and has adequate validity and reliability. <sup>41</sup>

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- 14 Diagnostic groups were categorized based on referral diagnoses (registered according to the
- 15 ICD-10 chapter without any further details) into: musculoskeletal, circulatory, and
- neurological diseases, neoplasms, and other (including various health conditions with < 50
- patients).

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- 19 Multimorbidity was defined as the coexistence of more than one self-reported chronic
- 20 conditions in the same individual. <sup>42</sup> based on the referral diagnosis and a predefined list of
- 21 self-reported chronic conditions. The list is reported elsewhere. <sup>29</sup>

- 1 Pain/discomfort was measured using the EuroQol 5 Dimensions 5 Levels (EQ-5D-5L). 43 This
- 2 instrument comprises five questions and a health rating scale. The questions assess physical
- 3 activity, psychological distress, and pain/discomfort. Pain/discomfort has five possible
- 4 responses, from no pain/discomfort to extreme pain/discomfort. Measurement properties of
- 5 the instrument have been tested extensively. 44

- 7 Age was categorized by decades. Marital status was dichotomized as married or unmarried.
- 8 The highest completed education level was categorized as primary school, high school, or
- 9 college/university. Smoking status was dichotomized as current smoking or not. Residence
- was dichotomized as rural or urban, with the cutoff being 20,000 inhabitants in the
- 11 municipality. Rehabilitation was dichotomized as initial (referred by a general practitioner) or
- ongoing management (referred by a hospital).

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# Statistical analysis

- 16 For descriptive statistics, mean and standard deviation (SD) are reported. To compare the
- female proportion and age distribution between participants and non-participants, exact chi-
- square and Mann–Whitney *U* tests were used.

- 20 Multiple linear regression analysis was used to study the effect of SOC on domain-specific
- 21 disability. Results are reported as estimated regression coefficients with 95% confidence
- 22 intervals (CI) and p-values from the F-test. The distribution of residuals was checked for

- adherence to assumptions of linearity, normality, and variance homogeneity. Analysis of
- 2 variance was performed using the F-test to investigate differences in SOC scores for variables
- with more than two categories. Tukey's post hoc test was used for subgroup comparisons.

- 5 Path analysis using structural equational modeling (SEM) was performed for two
- 6 hypothesized models (Figure 1). Satisfactory model fit was defined as a comparative fit index
- 7 (CFI) close to 0.95 or higher, Tucker-Lewis Index (TLI) close to 0.95 or higher, a root mean
- 8 square error of approximation (RMSEA) close to <0.06 or lower and cut-off close to 0.08 or
- 9 lower, and standardized root mean square residual (RMSR) close to 0.08 or lower. 45
- 10 Regression coefficients were examined for statistical significance. Estimated model
- parameters are given with 95 % confidence intervals.

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- All analyses were performed for the full sample and separately for diagnostic groups.
- 14 However, the structural models were estimable only in three diagnostic groups because the
- other groups were too small for valid analysis.

- Multiple imputations for missing items were applied according to the WHODAS 2.0 manual,
- 18  $^{30}$  with the number of imputation sets = 5. If the rate of missing WHODAS 2.0 items was >
- 19 50%, the data were excluded. Missing items in the SF-36 were managed according to the SF-
- 20 36 manual. <sup>32</sup> For the HADS and SOC-13, scores for patients with fewer than three missing
- 21 questions per subscale were included. For missing data, scores were imputed based on the
- 22 mean across each person's available responses for each subscale. For SEM analysis, listwise
- deletion was used, and no further imputation or adjustments were applied. The criterion for

- statistical significance was set at 5%. SPSS version 23 was used for all statistical analyses
- 2 except SEM where RStudio Version 1.0.143 with the lavaan package 0.5–23.1097 was used.

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# Results

- 6 In total, 984 of eligible patients provided responses and data of 975 patients were included in
- 7 the analyses (response rate, 34.6%). The mean age (SD) was 57.6 (14.0) years and 63.2% of
- 8 participants were women. Among non-participants the mean age (SD) was 55.6 (16.7) years
- 9 (p < 0.001) and 67.2% were women (p < 0.05).

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- 11 Main outcome measures could not be calculated for nine patients. After imputation for
- missing items, a WHODAS 2.0 overall disability score could be calculated for 967 patients,
- 13 SF-36 PCS and MCS scores for 885 patients, and SOC scores for 933 patients. For all scales
- 14 (and variables), missing values for items ranged from 0.4% to 4.2%, except for one
- WHODAS 2.0 item concerning sexual activities (12.8%).

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- 17 WHODAS 2.0, SF-36 (PCS and MCS), and SOC-13 scores are shown in Table 1. Men had
- significantly higher SOC scores than women (p < 0.001), and participants aged  $\geq$  50 years had
- significantly higher SOC scores than those aged < 50 years (p  $\le 0.01$ ). Participants with
- 20 circulatory diseases scored significantly higher than those with musculoskeletal diseases (p =
- 21 0.001).

- 1 Disability domains with mental components were associated with SOC, with lower disability
- 2 scores for higher SOC scores (Table 2). The estimated regression coefficients (95% CI) of
- 3 SOC on Cognition, Getting along, and Participation were -0.20 (-0.32, -0.08), -0.38 (-0.52,
- 4 0.25) and -0.23 (-0.36, -0.11), respectively. No significant interactions were found, and the
- 5 reported results were based on analyses with no interaction terms included.
- 6 The disability domain Getting along was associated with SOC for most diagnostic groups,
- 7 with lower disability score for higher SOC score, and associations with SOC were present in
- 8 some other domains for some diagnostic groups (Table 3).

- 10 The results from the SEM are shown in Figure 1 and Table 4. SOC had a positive association
- 11 with both HRQoL measures, mostly mediated by disability as better SOC led to reduced
- 12 disability which led to better HRQoL. The model fit was best for the subpopulation with
- 13 circulatory diseases. All models were significantly better than the independent model.

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# Discussion

- 17 To our knowledge this is the first study to assess the relationships between SOC, domain-
- 18 specific disability, and HRQoL in a large sample of rehabilitation patients with diagnoses that
- 19 are common in rehabilitation centers in secondary care. SEM was performed, in which two
- 20 structural models were investigated. The largest diagnostic groups were analyzed separately
- 21 to enhance the clinical relevance.

- 1 In comparisons with previous Norwegian studies, the mean SOC-13 score found in this study
- 2 was slightly lower than in a population of women after myocardial infarction <sup>46</sup> and higher
- than in a sample of patients with musculoskeletal pain, <sup>47</sup> consistent with the lower SOC-13
- 4 scores for patients with musculoskeletal diseases compared to patients with circulatory
- 5 diseases in the present study. The mean SF-36 domain scores in the present study (data not
- 6 shown) were lower compared with a Dutch study of patients in a rehabilitation center. <sup>47</sup>
- 7 However, the Dutch study was post-rehabilitation, 6–12 months after discharge. In our study
- 8 population, overall disability scores were higher than in similar populations of other studies.
- 9 48,49

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# Importance of SOC among rehabilitation patients

- 12 From a theoretical perspective, Antonovsky argued for an association between SOC and both
- mental and physical components of health, with better health according to stronger SOC.
- 14 However, the lack of association between SOC and the physical domains of disability
- 15 (Mobility, Self-care, and Life activities) found in the present study is consistent with a
- 16 previous systematic review. <sup>9</sup> An association between mental disability domains and SOC was
- found in all diagnostic groups and implies that rehabilitation patients with better capacity to
- cope report less disability in mental domains, also consistent with the same review. <sup>9</sup> Some
- 19 items in the Participation domain assess attitudes, reactions, and actions from significant
- 20 persons, which may represent aspects of social support that is positively related to SOC. 50

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- The results from the SEM in the full sample showed better fit of both hypothesized models,
- 23 including the mental components of HRQoL compared with the physical components, also in
- 24 line with previous studies. <sup>9</sup> This suggests that rehabilitation patients who are able to mobilize

- 1 available resources to manage challenges of everyday life, and who find this meaningful, may
- 2 have improved mental health. This was also found in a study where higher levels of SOC
- 3 predicted better mental health in men 3–6 months after a myocardial infarction. <sup>51</sup>

- 5 The fit indices for the hypothesized models found in patients with circulatory diseases support
- a direction of association from SOC to disability and mental components of HRQoL,
- 7 consistent with a previous study among adolescents with congenital heart disease. <sup>21</sup> However,
- 8 this comparison requires caution, considering the development of SOC in younger ages, as
- 9 theorized by Antonovsky. <sup>35</sup> The fit indices were also adequate considering the physical
- 10 component of HRQoL. To our knowledge, this has not been reported previously and further
- 11 investigation using longitudinal studies is needed to confirm that SOC actually improves the
- 12 physical component of HRQoL among patients with circulatory diseases.

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- Among patients with musculoskeletal diseases, the results from the path analysis did not
- 15 support the hypothesized models. We have not found any studies explaining this directly, and
- 16 future studies should investigate if SOC-related constructs such as pain, depression and
- 17 anxiety can explain why these relationships varies among different diseases. However, a study
- among patients with long-term musculoskeletal pain showed no association between SOC and
- work reentry. <sup>47</sup> Thus, the relationship between SOC, disability, HRQoL and other important
- 20 rehabilitation outcomes should be further investigated especially in this diagnostic group.

- 22 Although the WHODAS 2.0 measures the restriction on daily life activities and social
- 23 participation and the SF-36 addresses patient's physical and mental health, these constructs

- 1 overlap. Nevertheless, the results from the present SEM, which were numerically similar,
- 2 imply a different causal role of SOC.

- 4 Contrary to our hypothesized structural model, with the direction of association from SOC to
- 5 disability, the authors of a study investigating the association between SOC and disability
- 6 among elderly adults suggested an opposite direction. <sup>14</sup> For people experiencing disability, a
- 7 strong pre-existing SOC may be weakened <sup>14</sup>; the authors do not further specify the type of
- 8 this disability. Although Antonovsky postulated SOC to be relatively stable, he considered
- 9 that SOC could change under certain conditions. <sup>35</sup> Rehabilitation patients with activity
- 10 limitations and participation restrictions caused by their health condition may have their SOC
- 11 weakened, consistent with findings from a 5-year prospective population-based study showing
- that people with certain disease were among those with the largest decrease in SOC score over
- time. 52. Longitudinal studies are needed to assess whether SOC might be decreased before
- rehabilitation, and if rehabilitation efforts can restore the previous SOC.

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# Study limitations

- 17 The main limitation of this study is the cross-sectional design. We used our hypothesized
- 18 models to investigate whether data were consistent with causal links between the main
- 19 outcome measures, disability and HRQoL, and SOC as the main predictor. However, the
- 20 limitations of a cross-sectional design are well known, and the present findings can only
- 21 contribute to other evidence. Further investigations in this research area are needed to clarify
- 22 the importance of SOC in rehabilitation.

1 One third of invited patients consented to participate and a large number of survey

2 instruments were completed, indicating an acceptable response rate compared with other

3 large-scale surveys among rehabilitation patients <sup>4</sup> and in the general population. <sup>53</sup> The large

4 number of instruments used may explain some of the attrition. Nevertheless, the lack of data

5 from 65% of eligible participants limits the validity. The age of participants was slightly

6 higher than among non-respondents, which may lead to an overestimation of SOC scores as

these scores were highest among older adults. However, a lack of information on non-

participants makes it difficult to determine whether participants were actually healthier or had

stronger SOC. Further research should include larger samples with younger patients and with

other diseases. Most importantly, only a prospective design can give valid proof of causal

11 mechanisms.

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Conclusion

15 The present study indicates that SOC is related to mental domains of disability as measured

by WHODAS 2.0. However, the role of SOC in relation to disability and HRQoL seemed to

vary between the diagnostic groups. We believe that targeting SOC in the rehabilitation

setting especially in patients with circulatory diseases, could improve the mental components

of disability and HRQoL. Strengthening SOC involves enhancing patients' understanding and

reflection on stressful situations and the available resources and might help the patient to

engage in the rehabilitation process and take control of their own life. Future prospective

studies might clarify the role of SOC in achieving important outcomes in rehabilitation.

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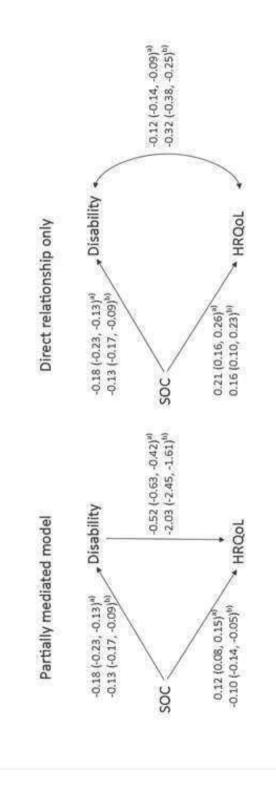
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6	Figure 1 Hypothesized structural models, including the results from structural equational
7	modeling among 975 patients accepted for specialized somatic rehabilitation in the Western
8	Norway Health Region during the first half of 2015. SOC = Sense of coherence; HRQoL =
9	Health-related quality of life; a) Estimated standard regression coefficients with 95%
10	confidence intervals for model including mental component score of HRQoL; b) Estimated
11	standard regression coefficients with 95% confidence intervals for model including physical
12	component score of HRQoL.
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15	Figure 2 Flow chart of patients accepted for rehabilitation at a rehabilitation center in
16	secondary care in the Western Norway Health Region during the first half of 2015.

Figure 1 Click here to download high resolution image



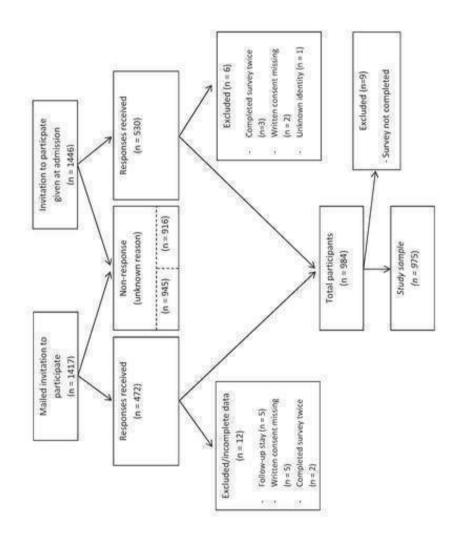


Table 1 Distribution of WHODAS score, SF-36 component scores and SOC score among 975 patients accepted for specialized somatic rehabilitation in

the Western Norway Health Region during the first half of 2015

			WHODAS score <sup>a)</sup>		SF-36 <sup>b)</sup>		SF-36°		SOC	
Variables		Female	(u = 967)		(n = 885)		(n = 885)		(n = 933)	
Categories	n <sup>e)</sup>	(%)	Mean (SD)	Ф	Mean (SD)	٥	Mean (SD)	ď	Mean (SD)	۵
All	984	63.4	30.8 (16.2)		32.8 (9.6)		43.6 (11.8)		62.9 (12.3)	
Gender				* * *		* * *		*		* * *
Men	360		27.8 (16.6)		35.1 (10.3)		45.1 (11.5)		65.2 (12.0)	
Women	624		32.6 (15.6)		31.4 (8.9)		42.7 (11.9)		61.6 (12.3)	
Age <sup>ή</sup> , <i>years</i>				* * *		* * *		* * *		* * *
18–29	28	75.0	33.5 (18.6)		37.0 (11.6)		39.8 (11.9)		53.3 (12.5)	
30–39	79	86.1	34.0 (16.1)		33.0 (9.0)		40.7 (10.1)		57.7 (13.7)	
40–49	180	69.4	36.1 (16.5)		32.9 (9.1)		39.9 (12.3)		58.6 (12.1)	
50–59	252	0.09	29.6 (14.4)		33.9 (9.7)		43.5 (12.2)		63.1 (12.2)	
69-09	241	58.8	27.6 (15.7)		33.6 (9.9)		45.3 (11.1)		65.4 (11.2)	
70–79	156	57.9	29.3 (17.0)		30.2 (9.3)		47.1 (11.3)		66.9 (10.4)	
≥ 80	48	58.7	31.3 (16.2)		27.1 (7.3)		47.9 (9.9)		67.9 (11.5)	
Health condition, ICD-10				* * *		* * *		* * *		*
Musculoskeletal diseases	457	75.9	34.4 (15.0)		29.6 (7.3)		42.5 (12.1)		61.7 (12.6)	
Circulatory diseases	187	33.7	23.2 (15.6)		38.9 (10.1)		45.8 (11.1)		66.1 (10.9)	
Neurological diseases	87	55.2	35.0 (16.3)		30.3 (8.7)		46.5 (10.6)		64.0 (11.7)	
Neoplasms	54	81.5	33.3 (16.8)		35.1 (9.0)		38.9 (11.6)		61.6 (13.2)	
Other <sup>g)</sup>	199	61.3	27.4 (16.0)		34.8 (11.0)		44.1 (11.7)		62.8 (12.3)	
Multi-morbidity				* * *		* * *		*		* *
Yes	635	65.7	32.9 (16.7)		31.7 (9.1)		42.7 (12.3)		61.8 (12.8)	
No	349	59.3	27.1 (14.5)		34.9 (10.2)		45.3 (10.8)		65.2 (11.0)	
Rehabilitation urgency				*		*				*
Elective	653	0.89	31.9 (15.9)		32.3 (9.3)		42.8 (12.1)		61.6 (12.6)	
Acute	274	53.6	27.6 (16.3)		34.6 (10.2)		45.8 (11.1)		66.5 (10.7)	

Unknown	57	57.9	34.9 (15.6)	29.9 (9.8)	43.2 (10.9)	61.1 (12.2)	
Marital status			*		* * *		* * *
Unmarried	455	6.69	32.3 (16.4)	32.6 (9.7)	41.4 (12.3)	60.9 (12.9)	
Married	525	57.9	29.6 (15.8)	33.0 (9.6)	45.5 (11.1)	64.7 (11.5)	
Unknown	4		23.7 (16.9)	31.2 (10.3)	47.6 (6.0)	65.5 (11.2)	
Educational level			*	* *			*
Primary school	205	8.89	33.6 (17.1)	30.6 (9.6)	43.6 (11.8)	60.5 (12.8)	
Secondary school	490	60.2	30.7 (16.1)	32.9 (9.9)	43.5 (12.5)	63.0 (12.2)	
College/university	278	66.2	29.0 (15.5)	34.3 (10.8)	43.8 (10.8)	64.5 (11.9)	
Unknown	11	66.2	32.9 (14.3)	30.7 (9.1)	43.8 (7.9)	64.4 (12.4)	
Smoking			*		* * *		* * *
Yes	184	7.07	34.1 (14.6)	31.9 (8.6)	39.2 (12.3)	58.1 (12.6)	
No	788	61.4	30.7 (16.4)	33.0 (9.9)	44.7 (11.5)	64.1 (12.0)	
Unknown	12	61.4	29.6 (16.0)	36.1 (4.9)	41.9 (9.5)	62.3 (8.7)	
Living area							
Urban	519	65.1	31.3 (16.1)	33.0 (10.0)	42.9 (11.7)	62.9 (12.3)	
Rural	465	61.5	30.3 (16.2)	32.7 (9.3)	44.4 (11.9)	63.0 (12.3)	

Abbreviations: WHODAS: World Health Organization Disability Score; SF-36 pcs: Short-Form 36-item physical component score; SF-36 mcs: Short-Form 36-item mental

mental component; d) 13 = lowest score, 91 = highest score (best); e) total included in the study; f) Mean (standard deviation): 57.6 (14.0) years; g) Diseases included the findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital influencing health status and contact with health services (n = 23), mental and behavioural disorders (n = 12), symptoms, signs, and abnormal clinical and laboratory a) 0 = lowest score of disability, 100 = highest score of disability; b) 0 = lowest score of health-related quality of life, physical component, 100 = highest score healthrelated quality of life, physical component; c) 0 = lowest score of health-related quality of life, mental component, 100 = highest score health-related quality of life, following: endocrine, nutritional, and metabolic diseases (n = 36), respiratory diseases (n = 37), injuries and external causes (n = 27), skin diseases (n = 24), factors component score; SOC: Sense of Coherence; ICD-10: International Classification of Diseases version 10; SE: standard error of the mean. malformations, deformations, and chromosomal abnormalities (n = 5); and certain infectious and parasitic diseases (n = 2).

\* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001 (F-test)

Table 2 Results of a fully adjusted linear regression analysis for predicting WHODAS 2.0 domain scores among 975 patients accepted for specialized somatic rehabilitation in the Western Norway Health Region during the first half of 2015

Predictor variable	Cog	Cognition	Mol	Mobility	Sel	Self-care	Gettin	Getting along	Life activities	tivities	Participation	oation
Categories	q	(SE)	Ф	(SE)	Ф	(SE)	q	(SE)	q	(SE)	Ф	(SE)
Intercept	8.32	(5.67)	-5.53	(8.03)	-8.63	(5.96)	32.87	(6.45)	9.02	(8.83)	23.53	(5.91)
Female (ref: male)	99.0	(1.22)	1.69	(1.72)	-0.99	(1.27)	-3.25	(1.38)*	7.07	(1.89)***	0.87	(1.26)
Age, years		*		* *				*				*
18–29	8.96	(3.40)	-3.69	(4.82)	1.93	(3.58)	-0.65	(3.87)	-5.15	(5.31)	-0.76	(3.56)
30–39	3.17	(2.24)	-9.39	(3.17)	-0.33	(2.36)	-2.11	(2.55)	2.10	(3.50)	2.76	(2.34)
40-49	5.35	(1.69)	-4.84	(2.39)	-0.72	(1.78)	4.96	(1.93)	4.97	(2.63)	3.24	(1.76)
50–59	1.41	(1.52)	-4.85	(2.15)	-2.11	(1.59)	-0.18	(1.72)	0.99	(2.37)	0.53	(1.58)
69-09	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
70–79	-0.86	(1.80)	6.63	(2.53)	2.34	(1.87)	-0.93	(2.06)	-0.31	(2.80)	-3.16	(1.88)
> 80	0.83	(3.00)	15.00	(4.18)	2.55	(3.11)	0.92	(3.40)	-3.29	(4.60)	4.30	(3.21)
Health condition		*		* * *		*		*		* * *		*
Musculoskeletal diseases	-0.52	(1.75)	10.23	(2.45)	0.87	(1.81)	0.31	(1.96)	5.85	(2.70)	2.67	(1.82)
Circulatory diseases	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
Neurological diseases	0.26	(2.28)	17.32	(3.22)	4.41	(2.38)	2.41	(2.59)	10.80	(3.58)	6.78	(2.38)
Neoplasms	7.85	(2.73)	3.52	(3.86)	-1.59	(2.87)	7.74	(3.10)	12.46	(4.26)	4.55	(2.80)
Other <sup>a)</sup>	-2.13	(1.79)	4.75	(2.52)	-2.56	(1.86)	-0.73	(2.02)	-0.85	(2.77)	-0.82	(1.86)

Multi-morbidity (ref: no)	2.81	(1.16)**	2.55	(1.64)	3.64	(1.22)**	1.62	(1.32)	4.66	(1.81)**	2.91	(1.21)*
Rehabilitation urgency (ref: elective)	1.58	(1.27)	5.32	(1.80)**	5.80	(1.33) ***	0.16	(1.47)	4.50	(1.98)*	2.52	(1.33)
Unmarried (ref: married)	-1.23	(1.12)	0.58	(1.59)	0.24	(1.18)	-1.19	(1.29)	1.25	(1.75)	-1.50	(1.18)
Education		*		* * *								
Primary school	4.84	(1.56)	8.70	(2.20)	3.41	(1.63)	-2.10	(1.76)	2.54	(2.43)	3.07	(1.63)
Secondary school	2.05	(1.24)	3.16	(1.75)	1.10	(1.30)	-0.93	(1.42)	3.28	(2.24)	1.51	(1.29)
College/university	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)	0.00	(Ref)
Current smoking (ref: yes)	2.61	(1.45)	0.63	(2.03)	1.01	(1.51)	0.97	(1.63)	3.81	(2.24)	2.08	(1.49)*
Rural municipality (ref: urban)	0.55	(1.09)	-2.15	(1.54)	-0.59	(1.14)	-0.01	(1.24)	-1.65	(1.70)	-0.90	(1.14)
EQ-5D (pain/discomfort) <sup>b)</sup>	0.50	(0.63)	8.47	***(0.89)	3.36	(0.66)**	1.42	(0.71)*	5.72	***(86.0)	4.12	(0.66)***
HADS-D score <sup>c)</sup>	1.69	(0.20)***	1.38	(0.28)***	0.84	(0.21)***	1.77	(0.22)***	2.48	(0.31)***	1.85	(0.21)***
HADS-A score <sup>d)</sup>	0.52	(0.19)**	-0.67	(0.27)*	-0.01	(0.20)	0.24	(0.22)	-1.01	(0.30)***	0.31	(0.20)
SOC score <sup>e)</sup>	-0.20	(0.06)**	-0.04	(0.09)	0.01	(0.07)	-0.36	(0.07)***	-0.11	(0.10)	-0.23	(0.07)***

Abbreviations: WHODAS: World Health Organization Disability Assessment Schedule; b: unstandardized estimated regression coefficient; SE: standard error; Ref: reference; EQ-5D: EuroQol EQ-5D; HADS-D: Hospital Anxiety and Depression scale, depression subscale; HADS-A: Hospital Anxiety and Depression scale, anxiety subscale.

a) Diseases included the following: endocrine, nutritional, and metabolic diseases (n = 37), respiratory diseases (n = 36), injuries and external causes (n = 26), factors influencing health

status and contact with health services (n = 23), mental and behavioural disorders (n = 13), symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); certain infectious and parasitic diseases (n = 2); b) From no pain/discomfort to extreme pain/discomfort, five categories; c) 0 = lowest score of depressive symptoms, 21 = highest score of diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital malformations, deformations, and chromosomal abnormalities (n = 3); and

\*\*\* p  $\leq$  0.001 (F-test).

Table 3 Results of a fully adjusted linear regression analysis for predicting WHODAS 2.0 domain scores in main groups of diseases among 975 patients accepted for specialized somatic rehabilitation in the Western Norway Health Region during the first half of 2015  $^{
m a)}$ 

Predictor variable	Cog	Cognition	Mo	Mobility	Se	Self-care	Gettir	Getting along	Life ac	Life activities	Partic	Participation
Diagnostic groups	q	(SE)	q	(SE)	q	(SE)	q	(SE)	٩	(SE)	٩	(SE)
SOC <sub>b</sub> )												
Musculoskeletal diseases	-0.23	(0.10)*	0.02	(0.12)	0.20	(0.10)*	-0.30	(0.11)**	0.07	(0.13)	-0.18	*(0.0)
Circulatory diseases	-0.32	(0.14)*	-0.22	(0.19)	-0.32	(0.15)*	-0.03	(0.14)	-0.18	(0.25)	-0.28	(0.15)
Neurological diseases	-0.04	(0.24)	-0.22	(0.37)	-0.06	(0.26)	-0.69	(0.24)**	-0.40	(0.42)	-0.48	(0.21)*
Neoplasms	0.18	(0.27)	0.38	(0.32)	0.07	(0.25)	-0.94	(0.37)*	0.34	(0.43)	0.41	(0.32)
Other <sup>a)</sup>	-0.21	(0.15)	-0.23	(0.24)	-0.20	(0.16)	-0.54	(0.17)**	-0.40	(0.23)	-0.27	(0.17)
Abbreviations: WHODAS: World Health (	Organizati	on Disability Ass	essment S	chedule; b: un	standard	ized estimated r	egression	Organization Disability Assessment Schedule; b: unstandardized estimated regression coefficient; SE: standard error; Ref: reference; EQ-5D: EuroQol	tandard e	ırror; Ref: refere	ence; EQ-5	D: EuroQol

EQ-5D; HADS-D: Hospital Anxiety and Depression scale, depression subscale; HADS-A: Hospital Anxiety and Depression scale, anxiety subscale.

a) adjusted for sex, age groups, multimorbidity, rehabilitation urgency, marital status, education, smoking, urbanity, pain/discomfort, depressive symptoms and anxiety symptoms; b) 13 = lowest score, 91 = highest score (best) b) Diseases included the following: endocrine, nutritional, and metabolic diseases (n = 37), respiratory diseases (n = 36), injuries and external causes

findings, not elsewhere classified (n = 9); codes for special purposes (n = 7); diseases of the digestive system (n = 6); diseases of the blood and blood-forming organs, and certain disorders involving the immune mechanism (n = 5); diseases of the ear and the mastoid process (n = 3); diseases of the genitourinary system (n = 3); congenital malformations, deformations, and (n = 26), factors influencing health status and contact with health services (n = 23), mental and behavioural disorders (n = 13), symptoms, signs, and abnormal clinical and laboratory chromosomal abnormalities (n=3); and certain infectious and parasitic diseases (n=2); \* $p \le 0.05$ ; \*\* $p \le 0.01$ ; \*\*\*  $p \le 0.001$  (F-test).

Table 4 Results from structural equational modeling for a prior hypothesized structural models of SOC, disability and HRQoL among 975 patients accepted for specialized somatic rehabilitation in the Western Norway Health Region during the first half of 2015

			Both models			Mode	Model 1 <sup>a)</sup> only	Mod	Model 2 <sup>2)</sup> only
Variables			Fit indices <sup>c)</sup>			Regressio	Regression coefficients		Covariance
Diagnostic groups	CFI	2	RMSEA (95% CI)	SRMR	SOC→Disability	SOC→HRQoL	Disability→HRQoL	SOC→HRQoL	Disability⇔HRQoL
SOC, disability, MCS									
All diseases	0.902	0.898	0.081 (0.080. 0.083)***	0.090	-0.178***	0.115***	-0.524***	0.209***	-0.115***
Musculoskeletal diseases	0.878	0.873	0.084 (0.082. 0.086)***	0.098	-0.211***	0.135***	-0.461***	0.233***	-0.116***
Circulatory diseases	0.980	0.979	0.038 (0.032. 0.043)***	0.093	-0.385**	0.153**	-0.409***	0.311**	-0.032***
Other	0.937	0.935	0.064 (0.06. 0.068)***	0.102	-0.408*	0.161*	-0.252***	0.264**	-0.058***
SOC, disability, PCS									
All diseases	0.852	0.847	0.093 (0.092. 0.094)***	0.103	-0.127***	***960.0-	-2.030***	0.162***	-0.318**
Musculoskeletal diseases	0.749	0.741	0.101 (0.099. 0.103)***	0.114	-0.161***	***960'0-	***296'0-	*650.0	-0.211***
Circulatory diseases	0.955	0.954	0.055 (0.051, 0.059)***	0.101	-0.294**	-0.026	-1.366***	0.375**	***960.0-
Other	0.894	0.890	0.081 (0.078. 0.084)***	0.115	-0.235*	-0.210*	-1.772***	0.205	-0.219***

Abbreviations: SOC: Sense of Coherence; HRQoL: Health-related quality of life; MCS: Mental component score of health-related quality of life; CFI: Comparative Fit Index; TLI: Tucker-Lewis Index; RMSEA: Root Mean Square Error of Approximation; SRMR: Standardized Root Mean Square Residual; PCS: physical component score of health-related quality of life. a) Partially mediated; b) Direct relationship only; c) Satisfactory fit of a model was defined by a CFI and TLI close to 0.95 or higher, an RMSEA close to 0.06 or lower, and an SRMSR close to 0.08 or lower [42]. \* p-value  $\leq 0.05$ , \*\* p-value  $\leq 0.01$ , \*\*\* p-value  $\leq 0.001$ 

## Errata for

Disability in patients entering rehabilitation centres in secondary care in Norway: A cross-sectional study of predictors and the relationships with sense of coherence and health-related quality of life

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## Errata

- Page 3 Missing word in third paragraph: «...on the theory and understanding of the under investigation. » correct to «...on the theory and understanding of the concepts under investigation. »
- Page 8 Error in description of score in fifth paragraph: «For all disability domains of WHODAS 2.0, a lower Hospital Anxiety and Depression Scale (HADS) score predicted lower disability score. » correct to «For all disability domains of WHODAS 2.0, lower scores of symptoms of depression predicted lower disability score. »
- Page 10 Missing words in Paper I title: «Validation of the World Health Organization Schedule 2.0 in specialized somatic setting.»—correct to «Validation of the World Health Organization Assessment Schedule 2.0 in specialized somatic rehabilitation setting.»
- Page 34 Error in description in first paragraph: «...coping by Sense of Coherence...» correct to «...life orientation by Sense of Coherence...»
- Page 35 Error in reference in fourth paragraph: «The history of WHODAS 2.0 has been described in section 1.2.3 of this thesis. » correct to «The history of WHODAS 2.0 has been described in section 1.4.3 of this thesis. »
- Page 43 Error in use of abbreviation in first paragraph: «...SEM...» correct to «...structural equation modelling...»
- Page 54 Error in sentence in fourth paragraph: «Construct validity, investigated by means of expected correlations between the WHODAS 2.0 and SF-36, was considered moderate compared with the SF-36.» correct to «Construct validity, investigated by means of expected correlations between the WHODAS 2.0 and SF-36, was considered moderate.»
- Page 58 Missing reference in fourth paragraph: «In older populations, symptoms of anxiety have been reported to increase disability only in women.» correct to «In older populations, symptoms of anxiety have been reported to increase disability only in women [132].»
- Page 60 Error in use of abbreviation in third paragraph: «...SEM...» correct to «...structural equation modelling...»
- Page 61 Error in use of abbreviation in first paragraph: «...SEM...» correct to «...structural equation modelling...»



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