UiT The Arctic University of Norway

Faculty of Health Sciences

Perceived quality of life and functioning after stroke in a region of North Norway and in a region of Central Denmark

A mixed methods study

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A dissertation for the degree of Philosophiae Doctor, January 2020

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Tromsø
2020

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HELSE NORD

Acknowledgements

Along this privileged journey with a steep learning curve, I am very thankful and grateful to my wonderful group of supervisors. *Cathrine Arntzen*, my main supervisor, for continually challenging me to dig deeper. Sometimes, I think you believe I can do more than is really possible – nevertheless, I choose to take that as a compliment. Further, your view of what takes ‘just a couple of hours’ has upheld my motivation when those ‘hours’ have dragged into several days or weeks of hard work. *Audny Anke*, you have been close to me in every aspect of this journey. The more I get to know you, the more I respect and honour your engagement, your knowledge and your kindness. *Oddgeir Friborg* for your statistical knowledge and discussions, teaching me ‘the difficult stuff’ that does not come to me easily. *Jørgen Feldbæk Nielsen* for your engagement in this project, and for your challenging questions opening my thoughts and perspectives.

I owe a great ‘thank you’ to my collaborative team and co-authors for engaging in data collection and manuscripts. The articles became better with your valuable and insightful comments. *Henriette Holm Stabel*, your contribution to this project has been of the utmost importance, and you deserve a medal for all your work, on top of your own research. *Guri Heiberg*, my nearest colleague and now a treasured friend. What would this journey have been like without you? I will hold on to you always!

I am grateful to my fellow PhD students both at UNN and at the UIT for all of the discussions, lots of humour during lunch breaks, and plenty of support. Special thanks to *Marit*, *Jill-Marit*, *Andreas* and *Ole Andreas* for critical evaluations, and helping me solve methodological struggles as well as technical issues. I am also grateful for my colleagues in *REFF* for all your support.

The Physiotherapy Department and especially *Anne Ringheim* for supporting the decision to do this work, and also for financial support for a pre-study visit to Denmark. This visit gave me useful insights of structure and organisation in the Danish region through formal and informal conversations with stroke survivors and health personnel across health care levels including: The Stroke Unit at Aarhus University Hospital, specialist rehabilitation services at Hammel Neurocenter, as well as rehabilitation services in Randers municipality. Additionally,

the Physiotherapy Department gave me the opportunity to attend an international conference of Mixed Methods Research prior to initiation of this project, giving me a lot of inspiration. Physiotherapy colleagues working in the department of neurology, and in particular *Trine Johansen* for taking charge of additional scoring and registrations – thank you all!

Ola Iversen and the Neurologic department of UNN Tromsø for support throughout this study, and for providing me with part-time work being responsible for registrations in the Stroke Registry.

Thanks to the bilingual translators for doing the back-translations, to my dear linguistic British friend *Angela Brady LeGrice* for all her language-checks, and to *Svein Henrik Hedenstad* for working on the graphical map with precise measures.

Last but not least, thanks to my family and my supportive friends. *Sten* for ‘holding the fort’ when I have been off on my ‘isolation-, high intensity-, and really necessary work-getaways’. To *Filip*, *Oliver* and *Emilie* for always putting a smile on my face, and for being such good kids.

> Every situation in life is temporary. So, when life is good, make sure you enjoy and receive it fully. And when life is not so good, remember that it will not last forever and better days are on the way.
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> Unknown

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Abstract

Background: The overall objective of this study was to explore quality of life and functioning one-year post-stroke in two Scandinavian country-regions with different organization of subacute rehabilitation services with a mixed methods approach.

Methods: A parallel mixed design was applied. Qualitative and quantitative data was collected in parallel, analyzed and published separately, and then - in this thesis - discussed together to gain a more comprehensive understanding of quality of life and functioning in the two country-regions. Reliability and validity testing of the Norwegian version of the Stroke-Specific Quality of Life (SS-QOL) scale, in-depth interviews and self-reported questionnaires was applied to enhance knowledge of long-term quality of life and functioning. Two studies (paper I and III) used quantitative methods and included stroke survivors from stroke units in the investigated regions in North Norway and Central Denmark, whereas one study (paper II) had a qualitative design and followed participants from in-patient rehabilitation until one-year post-stroke. Organisational differences of acute and subacute stroke rehabilitation services across study areas were described.

Results: The reliability of the SS-QOL scale was good, and the construct validity was supported. Two component scales were extracted from the 12 domain SS-QOL scale: The physical health (PH) component and the cognitive-social-mental (CSM) component. One-year post-stroke depression, anxiety, pre-stroke dependency, higher initial stroke severity, and advanced age were substantially associated to worsen SS-QOL scores across the country-regions. The levels of functioning measured by the SS-QOL scale, showed that the participants from the Danish region reported more functional problems in the SS-QOL scale and in the two components scales after adjustments for predefined covariates. Although the differences between the regions were significant, the magnitude was minor (small Cohens' *d*). The overall QOL-question of perceived change between pre- and post-stroke showed that half of the participants in both country-regions reported a negative change in QOL despite fairly good average functional scores. Description of acute and subacute stroke rehabilitation services revealed better organised municipality-based rehabilitation in the Danish region, and more use of in-patient rehabilitation in the North Norwegian region. The in-depth interviews revealed that the process of reconstructing the embodied self through progress or adjustments was an essential part of recovery and quality of life, thus bringing forward an understanding of QOL as a dynamic, relational and situational phenomenon that includes more than functioning. Enriching social relations, resumption of valued activities and professional support during the recovery process positively influenced reconstruction of the embodied self and QOL. Fatigue and sustained reduced function were described to affect QOL negatively.

Conclusions: This study found that the Norwegian version of the SS-QOL scale is a reliable and valid instrument with good psychometric properties, and suited for use both in individual assessments and in health research. The two country-regions differed in descriptions of continuity and support from the follow-up services during the recovery process, indicating benefits from the well-organized community-based rehabilitation in Central Denmark. Nevertheless, the quantitative results showed a statistically significant difference in the SS-QOL scores in favour of the Norwegian participants. Participants from both regions experienced significantly more problems within the CSM component than in the PH component, one-year post-stroke, indicating that longer-term functional improvements following mild and moderate stroke could benefit from rehabilitation services particularly addressing cognitive, emotional and social functioning in both country-regions.

List of papers

The three manuscripts included in this dissertation:

1. Synne Garder Pedersen, Guri Anita Heiberg, Jørgen Feldbæk Nielsen, Oddgeir Friborg, Henriette Holm Stabel, Audny Anke, Cathrine Arntzen. ***Validity, reliability and Norwegian adaptation of the Stroke-Specific Quality of-Life scale***. Published in *SAGE Open Medicine* 2018; 6: 1-10 https://doi.org/10.1177/2050312117752031

2. Synne Garder Pedersen, Audny Anke, Lena Aadal, Hanne Pallesen, Siri Moe, Cathrine Arntzen. ***Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis.*** Published in *International Journal of Qualitative Studies on Health and Well-being* 2019; 14:1 https://doi.org/1080/17482631.2019.165940

3. Synne Garder Pedersen, Oddgeir Friborg, Guri Anita Heiberg, Cathrine Arntzen, Henriette Holm Stabel, Gyrd Thrane, Jørgen Feldbæk Nielsen, Audny Anke. ***Stroke Specific Quality of Life one-year post-stroke in two Scandinavian country-regions with different organization of rehabilitation services. A prospective study.*** In review.

Table 1 Contributions to paper 1-3

Contributions	**Paper 1**	**Paper 2**	**Paper 3**
Concept and idea	**SGP**, CA, AA, GH, JFN, HH	**SGP**, CA, SM, LA, HP	**SGP**, AA, CA, GH, HHS, JFN
Study design and methods	**SGP**, AA, OF, GH	**SGP**, CA, AA	**SGP**, AA, CA, GH, OF
Data gathering and interpretation	**SGP**, GH, HHS, AA, OF	**SGP**, CA, AA, LA, HP, SM	**SGP**, GH, HHS, AA, OF, GT
Manuscript preparation	**SGP**, AA, OF, GH, HHS, JFN, CA	**SGP**, CA, AA, LA, HP, SM	**SGP**, AA, OF, GH, HHS, CA, JFN, GT

SGP: Synne Garder Pedersen, CA: Cathrine Arntzen, AA: Audny Anke, GH: Guri Heiberg, JFN: Jørgen Feldbæk Nielsen, HHS: Henriette Holm Stabel, OF: Oddgeir Friborg, LA: Lena Aadal, HP: Hanne Pallesen, SM: Siri Moe, GT: Gyrd Thrane

Apart from the three manuscripts included in this thesis, I also contributed to the following articles during the PhD period:

- Guri Anita Heiberg, Synne Garder Pedersen, Oddgeir Friborg, Jørgen Feldbæk Nielsen, Henriette Holm Stabel, Nicole von Steinbüchel, Cathrine Arntzen, Audny Anke**.** ***Can the health related quality of life measure QOLIBRI-Overall Scale be of use after stroke? A validation study***. Published in *BMJ Neurology* 2018; 18:98 https://doi.org/10.1186/s12883-018-1101-9

- Guri Anita Heiberg, Oddgeir Friborg, Synne Garder Pedersen, Gyrd Thrane, Henriette Holm Stabel, Jørgen Feldbæk Nielsen, Audny Anke. ***Health-related quality of life at 3 and 12 months post-stroke in a Central Danish and Arctic Norwegian Region: Satisfaction with functioning and predictors for change.*** Submitted.

Abbreviations

NORDA-study	The larger, main study
QOL	Quality of life
HRQOL	Health-related quality of life
WHO	World Health Organization
ICD	International Classification of Diseases
SAH	Subarachnoid haemorrhage
SIP	Sickness Impact Profile
SF-36	The Short Form (36) Health Survey
SS-QOL	Stroke-Specific Quality of Life
ICF	International Classification of Functioning, Disability and Health
EQ-VAS	The EuroQol Visual Analogue Scale
MMR	Mixed Methods Research
QUAN	Quantitative
QUAL	Qualitative
PROM	Patient Reported Outcome Measure
COSMIN	The consensus-based standards for the selection of health measurement instruments
mRS	modified Rankin Scale
SSS	Scandinavian Stroke Scale
HADS	The Hospital Anxiety and Depression Scale
EQ-5D	The EuroQol Quality of Life Scale
QOLIBRI-OS	The Quality of life after Brain Injury, Overall Scale
PCA	Principal component analysis
PH component	Physical Health component of SS-QOL
CSM component	Cognitive-social-mental component of SS-QOL
UNN	University Hospital of North Norway
AUH	Aarhus University Hospital
SEM	Standard error of measurement
χ^2	Chi-squared test
ICC	Intra-class correlation coefficients
STC	Systematic text condensation

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1 Introduction

The overall objective of this study was to explore perceived quality of life (QOL) and functioning following stroke in two Scandinavian country-regions with different frameworks for the organisation of rehabilitation services using a mixed methods approach. The study within this thesis constituted part of a larger prospective observational multicentre study, the ‘NORDA-study’, describing and comparing quality of life, functioning, rehabilitation pathways, and satisfaction with treatment and rehabilitation with both qualitative and quantitative approaches. The investigated regions are located in North Norway and Central Denmark. In this study, QOL is understood as an individual perceived experience. The methods applied are based on the stroke survivors’ own perceptions through in-depth interviews and through self-reported outcome measures to enhance knowledge of long-term QOL and functioning. Stroke survivors were followed from admittance to stroke units (paper I & III), or from in-patient rehabilitation (paper II) up to one-year following the stroke event.

Both quality of life (QOL) and health-related quality of life (HRQOL) are central terms in this study. We used the World Health Organization’s (WHO) definition of QOL (1) as the normative for the development of the study design for this thesis work:

> The WHO defines quality of life as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation of their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (1, webpage)

The term HRQOL has its origin in the more general concept of QOL. Despite the debate on which elements best constitute the HRQOL construct, western individuals would assert the ability to function well to be a central constituent of HRQOL. A challenging aspect of the construct is that several features in the life of a person will influence how their own HRQOL is perceived. For an individual with stroke, everyday life might change in many several ways. In this study, the HRQOL-measure applied mainly measured functions, and not well-being or satisfaction with life. Therefore, measurements of HRQOL and experience of QOL may for some individuals represent non-parallel dimensions. An objectively chronically disabled person may still perceive a satisfactory level of QOL, or conversely, a person with good HRQOL-measurement may experience QOL negatively. Thus. QOL is for these reasons a subjective and fundamental situated process that substantially shapes how an individual perceives their own experiences in life.

The process of rehabilitation following stroke may impact on QOL and functioning (2, 3). Rehabilitation services often involves multidisciplinary teams of health professionals with different perspectives towards the individual with stroke (4). The overall aim of rehabilitation is to reduce the consequences for the individual and to optimize functions – often within the framework of a biopsychological approach (5). For those who receive rehabilitation, this process may also have an impact on the mental process and counteract grief over the loss of functions. Hence, rehabilitation might contribute to a more flexible adjustment to a post-stroke life, and the individual may experience QOL through new modalities that can be perceived as meaningful and rewarding (6). Organization of stroke services is fundamental to quality of care, and covers the spectrum of care from prevention, acute care, and rehabilitation, to long-term follow-up services (7). Acute and sub-acute rehabilitation mainly focus on body functions and improvement of activities. Hereafter the focus might need to shift to a more adjusting, social and participating aspect when the individual returns to the usual environment (8).

Systems of care evolve in response to healthcare reforms, where rehabilitation is often considered a costly area to be reduced rather than recognized for its clinical impact on recovery, health and function (9). There is compelling evidence that stroke is highly preventable, treatable and manageable, and the potential exists to considerably reduce the burden of stroke and its long-term consequences (7). To meet this potential, knowledge about stroke survivors perceived functional outcomes and experience of quality of life in populations with different organisation of stroke rehabilitation services might improve our understanding of recovery in a long-term perspective. Previous studies have found variability in HRQOL-outcomes that could not be explained by demographics, stroke characteristics or service-related data alone (10, 11). Additionally, studies have found variability in functional recovery after rehabilitation across European countries (12, 13). Further knowledge of these perspectives is needed (10-13).

1.1 Stroke

The definition of stroke in this study is consistent with the WHO definition as; ‘rapidly developed clinical signs of focal, or global, disturbance of the cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin’ (14). Presently, the definitions of stroke are under discussion. The question of debate is whether to maintain the definition with inclusion of the patient’s clinical status by stroke specialists, or to base a diagnosis on radiology (15, 16). Definition of stroke is highly relevant for clinicians, researchers, and decision-makers as the definition determines incidence and prevalence across countries (15).

Stroke is a condition that is related to older age, although people of any age can be affected. In the present study, individuals with the two main types of stroke, ischaemic (as defined by the WHO International Classification of Diseases [ICD I.63]) or haemorrhagic (ICD I.61), are included. Ischaemic strokes include thrombotic infarction with atherosclerotic plaques, and embolic infarction (16, 17), which represented 86% of strokes in 2018, Norway (18). Haemorrhagic strokes refer to ruptured blood vessels and bleeding, often due to hypertension (16, 17), and occurred in 13% of strokes in 2018, Norway (18). Subarachnoid haemorrhage (SAH) has different treatment approaches than ischaemic and haemorrhagic stroke, and has not been included in the National Norwegian Stroke Registry (18).

Age-adjusted mortality rates for ischaemic and haemorrhagic stroke decreased globally between 1990 and 2015, but the absolute number of individuals experiencing stroke, and the years lived with disability increased (19). Stroke remains a common cause of death and disability in Europe, and the burden of stroke is not expected to decrease in the next decade or beyond (7, 20). An important factor for the rise in prevalence of stroke and its costs, is that the number of older individuals in Europe is growing and is expected to increase by 35% between 2017 and 2050 (21, 22). However, the Nordic countries show a decreasing trend in incidence-rates (23, 24). A recent Norwegian report showed a 13% decrease in reported strokes from 2012 to 2018, and an increase in survival rates of 1.6% from 2013 to 2018 (24). Nevertheless, those who survive a stroke often suffer from varying functional disabilities that affect opportunities to participate in everyday life (20), and increase the years lived with disability (25). Long-term consequences, such as perceived impact on QOL (26, 27) or HRQOL (28, 29) have been increasingly documented in studies.

1.1.1 General consequences following stroke

Chronic conditions and functional impairments are both assumed and reported to diminish an individual's QOL (30) and HRQOL (31). Different impairments and functional difficulties following stroke may occur in a variety of combinations or as one single problem (8, 32). Stroke survivor's wide variety of functional challenges within for example motor (33, 34), sensory (35, 36), cognitive (37), visual (38), communicative (39, 40) or emotional (41) areas may persist for a considerable time. The long-term effect is determined by the initial stroke lesion and by the extent of subsequent recovery (42).

Impairments, even in mild strokes, can be 'hidden dysfunctions' difficult to discover in a hospital setting (43). Disabilities may concern physical limitations, such as paresis, or psychological and cognitive problems, such as depression or memory deficits (44). Up to one-third of stroke survivors may be affected by post-stroke cognitive impairments (45). Subtle cognitive impairment commonly is not always clearly evident, particularly when the stroke survivor seems to have recovered functionally in other aspects (45, 46). Stroke survivors with anosognosia have been found to be more unaware of their cognitive impairments than their motor or sensory impairments (47), and one study (48) found that stroke survivors omitted considerations of their cognitive problems when communicating with health professionals on their post-stroke recovery.

Individuals with stroke are a heterogeneous group with various needs both due to their diverse functional difficulties and their individual differences in recovery, personal factors like motivation and expectations, as well as contextual environmental circumstances (5, 8, 48, 49). A considerable group of stroke survivors experience persistent disabilities, even years after the stroke (50). Many stroke survivors return to their previous living environment, where they can be confronted with difficulties in managing their activities, and resume their former participation-level and social roles (44, 48, 51, 52) – which might impact on QOL and HRQOL.

2 Theoretical framework

2.1 The wide-ranging concept of Quality of Life

There is a wealth of data on quality of life (QOL) and individuals with stroke. A PubMed search (October 21, 2019) revealed over 6,000 articles using the combination of search terms 'stroke' and 'quality of life' limited to the last 10 years. QOL is a broad multifaceted concept that usually includes subjective evaluations of both positive and negative aspects of life. However, QOL may convey many meanings both for the individual and researchers (53-58). The terminology of 'quality of life' is commonly used as outcome in a variety of studies and measures, and interpretation of results is severely limited by the general lack of consensus on how to define and measure QOL(56).

QOL has been discussed in the medical literature since the 1960s (59), and has become more important in health care as medical treatment extends the life-span of patients. As a consequence, patients live longer with different disabilities, with pain, or in a palliative state; sometimes at the expense of their QOL (60). Health and health status have become central terms as a means to understand aspects of QOL. Health was defined by the World Health Organization [WHO] in 1946, and the definition has not been amended since 1948 (61). According to the WHO definition, 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (61, p.100). The term of QOL is rooted particularly in health science fields as a concept both for the evaluations of individual experiences and subjective health-measurement (30, 31, 62).

2.1.1 Health-related quality of life and measurement

At the time when health-related QOL (HRQOL) measures were introduced, HRQOL was defined as a subset relating to the health dimension of QOL(63), and subsequently as a component of QOL that is directly or indirectly affected by health, disease, disorder and injury – hence overlap the concept of health status (53, 56, 64). Many researchers and clinicians treat the terms 'HRQOL', 'QOL', 'health', 'perceived health' and 'health status' synonymous (56), which may lead to confusion about the HRQOL-term. Some of the most well-known HRQOL-measures were initially not presented with the 'HRQOL-label': For example, the Sickness Impact Profile (SIP) (65) was presented as a health status measure, and the 36-item

Short Form Health Survey (SF-36) (66) was presented as a health status survey – nevertheless they both turned into and became HRQOL measures at some point (53, 56). Accordingly, HRQOL has no single accepted definition (57, 60, 67), but it is assumed to be a broad multidimensional construct referring to those aspects of people's lives that reasonably relate to their health (57). Enhancing HRQOL is an overall goal in rehabilitation (68), and therefore an important outcome measure to inform and shape rehabilitation practice, research and theory (69).

Several instruments have been developed and have helped conceptualize and measure QOL. HRQOL commonly is used to focus on the perceived impacts of illness and treatment on patients (31, 67), or as an indicator of successful and high-quality health services (30, 31, 62). There are QOL instruments that consist of one question of life as a whole, and that have been found valid in several studies (70). However, such comprehensive questions have been critiqued for being greatly influenced by the situation that the respondent envisions when the question is answered. Other HRQOL instruments are multidimensional, meaning that they exhibit several aspects or dimensions (57, 58). However, comprehensiveness of dimensions in each instrument varies considerably, and the HRQOL-instruments include a variety of different aspects, for example subjective well-being, satisfaction, self-perception on physical and/or mental health, functions, activities, participation, or a wide combination of several aspects (56). Self-reported instruments are important as they measure the individuals' perceived impact of stroke on different aspects of their life situation and provides a portrait of health-related aspects of QOL.

Although comparability of HRQOL results can be limited due to divergent definitions (60), operationalisation, and measures (56), these measures are undoubtedly important in gaining an understanding of the ways in which health conditions or disablement impact on different aspects of stroke survivors' lives (30, 57, 67). The results obtained may inform how governments and other institutions on how to develop targeted strategies to improve life circumstances both at a group level and at an individual level (30). HRQOL may be generically measured if comparison across populations with diverse diseases is of prime interest, or alternatively, measured specifically for the actual disease. Both generic and stroke-specific HRQOL instruments are commonly used in research following stroke (57, 58, 67, 71). Much of the discussion concerning HRQOL measurement involves the advantages and disadvantages of generic versus disease-specific instruments (53). Some of the generic instruments are brief and completed efficiently (72, 73), although some are quite extensive to complete (66, 74). Another potential advantage of some generic measures is that they can be used for calculating utility values in cost-effectiveness analysis. However, they are considered to be less sensitive for detecting small but clinically important differences in intervention and treatment effects (67, 75, 76), and they are unable to embrace detailed problem areas related to a specific disease (53, 57). For stroke, dimensions of language/communication, fatigue, cognitive functions, and vision are typical areas often not included in generic measures. Stroke-specific HRQOL scales tend to be broader and more comprehensive (57), but there is a scarcity of stroke-specific instruments to measure HRQOL in the Norwegian language. In the current study, different aspects of self-reported functioning and capacity, social roles, mental and emotional states were measured by the Stroke-Specific Quality of Life (SS-QOL) scale. However, we could not measure subjective well-being (77) or life satisfaction (78, 79) with the chosen measurement.

Very few studies of stroke-specific HRQOL have been reported across countries (80), and none good-quality or European studies were found. However, we did find two studies using generic measures that showed variability in HRQOL-rankings across Western and European countries that could not be explained by demographics, stroke severity or service quality related data (10, 11). Both studies emphasized the need to investigate these matters further.

Important predictors of HRQOL in stroke survivors

Predictors of HRQOL have been extensively investigated with both generic and stroke-specific instruments. Older age, higher stroke severity, functional status or disability at discharge from hospital, and mental health problems are frequently mentioned as important predictors of worse HRQOL in stroke survivors across diverse countries and continents (28, 29, 32, 58, 71, 81-84). Studies from Scandinavia (85), Canada (86), Australia (87) and the USA (88) have reported gender differences in stroke recovery and a worse functional outcome for females after stroke, as well as worse HRQOL measured with both generic and stroke-specific instruments (58, 87). Nevertheless, other studies did not find gender to have a significant impact on either generic or stroke-specific HRQOL (71). Inclusion of well-documented or contradictory predictor variables in regression analyses can bring out their respective contribution to HRQOL in the investigated regions of Norway and Denmark.

2.1.2 Quality of life – more than health

QOL is more than health status, clinical symptoms, or functional ability – health is only one dimension of QOL (89). When investigating QOL from a self-experienced qualitative approach, context and meaning are highlighted, hence researchers are implicitly opening up to other aspects beyond health in the concept of QOL. The individual's perspective has been highlighted as an essential component of the definition because QOL rests in the experience of life, and its essence lies in the person's own evaluation of the experience (89, 90). Qualitative interview-studies are suitable for an empirical exploration of these experiences with different aspects of QOL in the contextual setting of each individual. Interview studies can gain insight into how people understand and experience particular circumstances and find meaning in life.

A qualitative meta-synthesis (26) of previous research on stroke survivors' QOL, identified nine central themes; physical and cognitive changes, communication, sense of self and identity, activities and participation, dependency and social support in relationships, uncertainty and level of control, adaption and attitude, personal and social interpretation, and new values and perspectives. The variability in all these themes suggests a great variety in the individual's experience of QOL. In several of the included studies, impairments and disabilities were identified as a major source of distress having a negative impact on QOL(26). However, a few studies have stated that not all participants experienced a reduced QOL based on the lasting functional problems of stroke (91, 92). Individual differences of perceived QOL have been reported to be radically different even if the consequences were objectively similar (26, 92), as well as related to individual reference points in the pre- and post-stroke perceptions of life (93), and transitions or shifts in values and perspectives (27, 94-96). Some of the studies found changes in sense of self or identity (91, 94), and changes in roles or loss of roles (27, 94) that negatively impacted on their QOL. In contrast, one study (95) determined that identity-problems was not an issue for all participants. Other meta-syntheses (97, 98) have explored experiences with life after stroke, but not with the QOL-perspective. However, a major finding across all the above-mentioned studies was the unsystematic, dynamic processes of adapting, reinventing or transforming, and rebuilding a post-stroke life and identity.

We did not find any qualitative studies investigating QOL across country-regions in the available literature, although differences in cultural factors, health systems, and available resources have been suggested as explanatory factors for the variability in post-stroke HRQOL across western countries (10, 11).

2.2 Rehabilitation after stroke

2.2.1 Definition of rehabilitation

According to the World Report on Disability (World Health Organization [WHO] 2011), rehabilitation is ‘a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments’ (99). The Norwegian definition (100) includes both habilitation and rehabilitation:

> Habilitation and rehabilitation must be based on the individual situation and goals of the individual patient and user. Habilitation and rehabilitation are targeted collaborative processes in various arenas between patient, user, relatives and service providers. The processes are characterized by coordinated, coherent and knowledge-based actions. The purpose is that the individual patient and user, who have or are at risk of being restricted in their physical, mental, cognitive or social functioning, should be given the opportunity to achieve the best possible functional- and coping ability, independence and participation in education and working life, socially and in the society (100, webpage)

The Norwegian and Danish definitions of rehabilitation are quite similar, although the Danish definition has an element of time-limitation.

2.2.2 International Classification of Functioning, Disability and Health

WHO’s framework International Classification of Functioning, Disability and Health (ICF) is a perspective for structuring different consequences following a disease or health-condition, both at the individual and population levels (5). The framework is often used by rehabilitation services as a biopsychological approach for documentation and structured planning of treatment in relation to the individual. ICF conceptualizes functioning as a dynamic interaction between a person’s or groups’ health condition, environmental factors, and personal factors (101). In rehabilitation, functioning is commonly documented within the ICF-framework (102), and operationalised into *biological health* as ‘body functions and structure’ and capacity (limitations) across ‘activities’ and ‘participation’ (5). Further, functions as the *lived health* relates to what a person actually does, or is restricted in doing in his/her environment, assessed as performance across the levels of ‘activity’ and ‘participation’(102, 103). Participation is defined by the WHO as involvement in one's own life situation, and includes taking part in activities, being engaged in different life areas, and having access to necessary resources (5). Several studies have combined self-experienced perspectives, or outcomes in HRQOL measures, using the ICF-perspective of body functions, activities and participation (104-107) , as well as the importance of contextual influence of personal and environmental factors (108). In this thesis the framework of ICF was useful as a perspective in discussing the results of functioning.

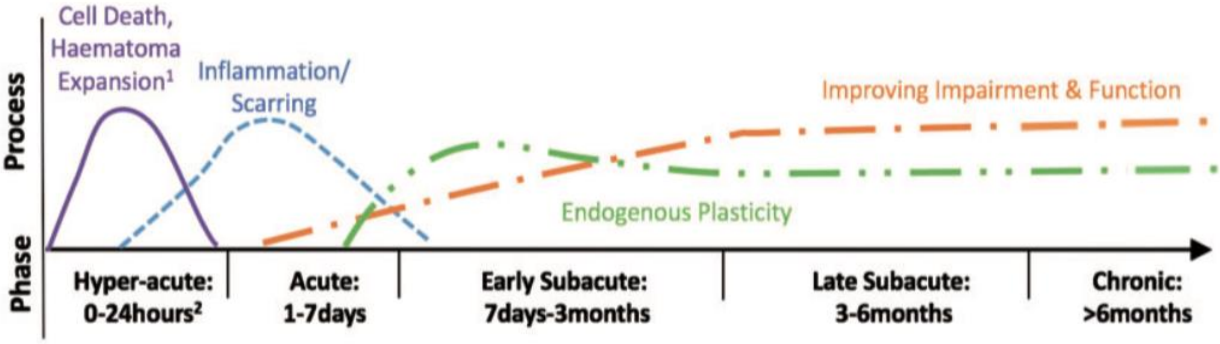
2.2.3 Recovery

Evidence for neuroplasticity in the brain (109, 110) has improved both rehabilitation research and treatment for stroke survivors with long-term disability (111). The term recovery is often debated, and several argue for distinguishing *recovery* as a 'true' reorganization of connectivity patterns of neurons in the brain, from *compensation* that refers to the substitution for, or circumvention of impaired functions (112-114). One example of compensation in partial visual field loss, is compensatory head and eye movements to help fill in the field (115).

In this study, recovery mirrors the extent to which body structure and functions, as well as activities and participation, are restored to a more normal, pre-injured state (111, 114), and the term recovery also includes compensations in the form of adjustments to, or adaptations to a post-stroke life. These processes within recovery are individual, and do not always coincide in time (113, 116). The process of adjustment is one example of a commonly documented (117) long-term process in recovery. Along with these individual processes, profession-specific definitions used to describe recovery in clinical rehabilitation and research are not always overlapping and may confound interdisciplinary communication (111). Nevertheless, recovery after stroke is a multifaceted process (118, 119) that probably depends on both spontaneous and learning-dependent processes (42, 113), requiring teamwork and dialogue in rehabilitation (111).

These abovementioned issues represent some of the complexity of stroke rehabilitation research. Bernhardt et al.(114), recently stated, 'Definitions within stroke recovery research are particularly complex given both the extended time window over which research, clinical interventions and recovery take place; and the multi-disciplinary, multifaceted nature of this field' (114, p.444).

The timeline of stroke recovery and the terms ‘acute’, ‘subacute’ and ‘chronic’ are often used in recovery research with no specific definition (114). However, the Stroke Recovery and Rehabilitation Roundtable taskforce (114) recently recommended standardised definitions of critical time-points for post-ischaemic and haemorrhagic stroke that relates to the current known biology of recovery (Figure 1):



[1] Haemorrhagic stroke specific. [2] Treatments extend to 24 hours to accommodate options for anterior and posterior circulation, as well as basilar occlusion.

Figure 1 Timeline of stroke recovery

Reprinted from the International Journal of Stroke, Volume 12/Issue 5, Bernhardt J, Hayward KS, Kwakkel G, et al. *Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce*, p. 446, Copyright (2017), with permission from Sage Publications/Copyright Clearance Center’s RightsLink.

The term ‘chronic’, as described above, might suggest associations to a non-developing state for the stroke survivor. However, new motor patterns can be developed in response to motor learning even a long time after stroke (111, 112, 120). Likewise, the process of adjustment and adaptions to a post-stroke life is usually a long-term process influencing recovery of stroke survivors (51, 117).

Recovery from a qualitative perspective

Studies have investigated recovery in the process of rehabilitation as a lived and self-experienced phenomenon (6, 51, 97, 117, 121-124), identifying different patterns, transitions, and phases in the long-term trajectories after stroke. Multifaceted, individual, and contextual interrelations are emphasised throughout the transformative process of rehabilitation to gain knowledge of how health professionals may support stroke survivors, and/or their caregivers, in different aspects within the system and those people with whom they interact (125). This research has the ability to capture subjective dimensions of life and rehabilitation after stroke by exploring concepts and processes essential to the individual through the lived experience (98, 125). One meta-synthesis (98) that summed up a number of qualitative reviews on this area, identified five dominant themes across a significant number of studies: autonomy, uncertainty, engagement, hope and social relations. Nevertheless, the authors emphasised the importance of evaluating findings in relation to different studies' geographical context, various demographics of stroke survivors, stroke severity, time of interview, and rehabilitation services available to the individual to translate the themes into clinical recommendations (98). This is an important supplementary statement, as qualitative rehabilitation research is a naturalistic inquiry reflecting context sensitivity by placing research within social, historical and temporal context in which they exist (125).

2.2.4 Organisation of rehabilitation services after stroke

Although there has been an explosion of knowledge about the stroke-damaged brain (113), and several new treatment options in modern medicine, most post-stroke care will continue to rely on rehabilitation to promote functioning and QOL (42, 126). Structured multi-disciplinary stroke rehabilitation has been found to reduce stroke-related disability both in older and younger stroke survivors independent of gender or stroke-severity (127, 128). Hence, multidisciplinary rehabilitation is a central principle of high-quality stroke care (4). Rehabilitation can be offered in a wide range of settings, including acute and post-acute care, inpatient rehabilitation units, early supported discharge, outpatient or ambulatory care services, and rehabilitation in municipalities (126).

Stroke rehabilitation is generally recommended to start shortly after the initial stroke event and when the patient is medically stable, to maximize functional gains (126, 129, 130). However, individualized clinical judgement and caution are indicated in some cases, and especially with intracerebral haemorrhage (131). A systematic review evaluated care in stroke units compared to treatment in medical wards, and demonstrated reduced mortality as well as increased likelihood for independence and living at home the first year after stroke, regardless of age, sex, disability, stroke severity, or stroke subtype (128). Although there is compelling evidence for better outcome when patients are admitted to stroke units with combined multidisciplinary acute care and in-patient rehabilitation (128, 132, 133), there is less evidence regarding rehabilitation services beyond discharge from these units (4, 114, 134). However, effects of early supported discharge (135, 136) have proved effective. A Cochrane review (135) reported reduced long-term dependency and admission to institutional care, as well as reduced length-of-stay in hospital for a selected group of individuals with stroke if the early supported discharge services were appropriately resourced and had coordinated multidisciplinary team input. However, the results were inconclusive for services without coordinated multidisciplinary team input (135).

A recent Norwegian survey-study investigating the effect of team collaboration and continuity of care among patients receiving rehabilitation in different regional rehabilitation centres (not diagnose-specific), found that better personal, team- and cross-boundary continuity of rehabilitation care was associated with improved reported patient health (measured with EQ-VAS) after rehabilitation at the 1-year follow-up (137). A systematic review (138) assessed the effectiveness of different forms of multidisciplinary care (versus standard care) delivered to community-dwelling stroke survivors after discharge from hospital or inpatient rehabilitation, with outcomes of activities of daily living, social participation, and QOL. Two of the included studies reported favourable effects of multidisciplinary teams in regards to HRQOL (138). How to best provide long-term support for stroke survivors requires knowledge and understanding of community-based services, and there is a need for further investigations of the long-term effects of rehabilitation following stroke (4, 138).

Discipline-specific interventions after stroke have also been investigated. For example, Pollock et al. (139) conducted a larger review of physical rehabilitation following stroke, and concluded that different approaches are effective for recovery of function and mobility, but no single approach was found to be any more or less effective in promoting recovery of function and mobility. One of the ‘problems’ of conducting discipline-specific research in a rehabilitation setting, is the impact of other simultaneous interventions from the interdisciplinary team, and the ethical aspects of potentially not treating stroke survivors with the best knowledge-based approaches available within each discipline. The ‘winning ingredient’ of team work is established, but what this ingredient consists of is more challenging to pin down (4).

Inequalities in accessing inpatient rehabilitation after stroke have been reported in many countries (140, 141). Similarly, organization of rehabilitation services after discharge from stroke units and inpatient stroke rehabilitation differ between countries (13, 142) and within countries (142, 143).

2.2.5 Organisation and rehabilitation in the study-regions

The present study is an international multicentre study with participants living in the geographic area of the University Hospital of North Norway (UNN), and two municipalities in Central Denmark associated to the University Hospital of Aarhus (AUH). The first part of the study (paper 1) includes only the geographic area of North Norway.

Health care in both Norway and Denmark includes two complementary public sectors: regional specialised hospital services and the primary municipal health care system. There are several organisational health system country differences, but common to the two countries are 1) the specialist level, which includes specialised stroke hospital units and specialised rehabilitation units, and 2) the municipality receives responsibility when an individual with stroke is discharged from the hospital stroke unit or from inpatient rehabilitation. To optimise seamless and fluent transitions between the two health care levels, intermediate outreach teams have been established in both countries. Both Norway and Denmark have national clinical guidelines following stroke (129, 130) recommending team-based, interdisciplinary organisation to provide holistic rehabilitation. High admittance rates to stroke units (<90%) are comparable in the two countries, as well as the high survival-rates post-stroke and well-organised stroke unit acute rehabilitative treatment (144, 145).

Although both countries are fairly equivalent when it comes to welfare society, life expectancy, and cultural aspects, the two regions investigated in North Norway and Central Denmark differ in terms of geographical areas and settlements. Differences exists in how rehabilitation is organised with both specialised and highly specialised levels within the regional specialist level and centralised/large units of care in Denmark versus more decentralised/small health care units in Northern Norway. Additionally, Danish treatment and rehabilitation recommendations were, at the time of the study, substantially more detailed and explanatory when referring patients to the next level after discharge from stroke units. Furthermore, additional levels were described in the guidelines (130, 146). Qualitative studies with stroke participants and health professionals in the respective regions, have reported higher availability to, and better organisation of municipal rehabilitation services in the Central Denmark region than in the region of North Norway among the interviewed individuals (142, 147, 148). Accordingly, region-specific organisational factors may impact on the aim of equality in post-stroke care, functional recovery, and QOL both within regions and between regions. More specific organisational differences between the country-regions are described in the methods-section.

2.3 Aims of the Ph.D. project

Few studies have compared stroke-specific HRQOL or QOL across countries with differing organisation of rehabilitation services, and there is a paucity of stroke-specific HRQOL measures in the Norwegian language. The overall objective of this study was to explore the perceived QOL and functioning following stroke in two Scandinavian country-regions with different organisation of subacute rehabilitation services using a mixed methods approach. A parallel mixed design was applied. Qualitative and quantitative data were collected in parallel, analyzed and published separately, and then - in this thesis - integrated and discussed together to gain a more comprehensive understanding of quality of life and functioning in the two country-regions.

The overarching question of interest

How do stroke survivors in North Norway and Central Denmark perceive QOL and functioning one-year post-stroke, and could country-regional differences in organisation of subacute rehabilitation services be associated with their experience?

Specific aims were:

- To translate, cross-culturally adapt and validate the Stroke-Specific Quality of Life (SS-QOL) scale for use in the Norwegian population

- To understand how stroke survivors' experienced QOL during the first year of recovery in North Norway and Central Denmark

- To describe and compare levels and profiles of the SS-QOL scale between cohorts from specified municipalities in North Norway and Central Denmark Region one-year post-stroke

- To investigate whether country-regional differences were associated with SS-QOL scores after accounting for selected covariates, and to examine whether the demographic, stroke-related, or psychological factors were associated with SS-QOL scores

3 Materials and Methods

3.1 Methodology, rationale, and philosophical worldview

This project was built around the overarching research question, and both qualitative and quantitative methods could be used to gain relevant knowledge. Therefore, I chose to conduct a mixed methods study with a complementary aim (149), meaning that the use of both qualitative and quantitative data can bring together a more comprehensive account (149-153) of the perceived experience of quality of life (QOL) and functioning following stroke. The quantitative questionnaire data provides an account of structures (150) in the participants life following stroke, whereas the qualitative in-depth interviews provides sense of process (154) and situatedness. Contextual understanding through in-depth interviews can be coupled with broad relationships among variables uncovered in the questionnaires. The different sub-studies answer different research questions, and the sum of these questions could bring a fuller understanding of the overarching research question of perceived QOL and functioning following stroke. Hence, my rationale in conducting a mixed methods study involves *completeness, process and context* (150, 151). Mixed methods research (MMR) to investigate the stroke experience has been proposed (155), and studies have pointed out the need for investigation of QOL (30), as well as QOL and stroke (26) using mixed methods approaches due to the complexity of the phenomenon.

MMR involves not only the joint use of qualitative and quantitative methods or data, but also their integration (149, 152, 153, 156), which involves some sort of gathering of the results, such as a discussion or synthesis. Within this thesis, the main results are compiled and discussed transversely to gain a deeper and more complete understanding of the phenomenon.

This dissertation is based on the following definition of MMR by Johnson et al. (157):

> Mixed methods research is the type of research in which a researcher or a team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration (157, p.123).

This choice of approach to research involves certain philosophical assumptions as well as distinct methods or procedures (158, 159). A pragmatic scientific theory was undertaken as my philosophical worldview in this study. Very broadly, pragmatism is a philosophical tradition that understands knowing the world as inseparable from the agency within it (160), thus it expands opportunities to use multiple methods, different worldviews, and assumptions and different forms of data collection and analyses (158). Pragmatism involves emphasising the research problems and using all approaches available, and is a common philosophical stance in mixed methods research that uses pluralistic approaches to derive knowledge (152, 158).

Research paradigms within qualitative and quantitative approaches are commonly seen as polar opposites or dichotomies, or alternatively, they represent different ends on a continuum, where mixed methods research resides in the middle of this continuum because both qualitative and quantitative approaches are incorporated as elements (158). Pragmatism is not committed to any one system of philosophy and reality; the truth is what works at the time (154, 158). Hence, ‘what works’ is a practical orientation towards problem-solving, and easily applies to selecting the methods that ‘work’ best to address this study’s problem and questions instead of focusing on the methods (154, 158). However, the value of pragmatism as philosophy for research requires overcoming the emphasis on practicality (161), and describing the philosophical assumptions that underpin research, for example, why to do research in a given way.

In this study, I rely on John Dewey’s philosophical standpoint within the different orientations of pragmatism. Dewey’s theory of knowledge offers an understanding of knowing that is not premised on the dualistic objectivity *or* subjectivity, thus, instead put forward a framework that starts with interactions (162). These interactions in the world could not be understood separately from the environment, or the context or situation, in which living organisms are implicated (161, 162). According to Dewey, a *situation* is a determinative for the onset and course of individual experiences (162, 163), hence all experiences can be understood as contextually constructed. There is a central link between Dewey’s perspective and the phenomenological hermeneutic understandings, which is a central theoretical framework in the qualitative part of the study. Dewey as well as Gadamer and Heidegger, frame experience derived from co-existence in particular settings (163, p.3). Dewey’s epistemology relates well to Merleau-Ponty’s (164) understanding of experience as embodied and situated. Situatedness refers to involvement within a context, is central for the lived experience, and precedes any articulated experience.

Dewey’s pragmatism is helpful in highlighting the importance of combining beliefs and actions in a process of inquiry that underlies any search for knowledge (161). In this mixed methods study, this is important to make the case that different approaches generate different outcomes, and that priorities of both approaches can generate a broader understanding of a phenomenon of interest, such as QOL and functioning. A pragmatic worldview was also appropriate within the overarching NORDA study as a whole, as the multidisciplinary research team was planning to collaborate on both qualitative and quantitative data.

3.1.1 Study phases and design

In designing this study, a four-phase study was planned. The first phase included initiation of collection of both qualitative and quantitative data. The second face included validation of a stroke-specific health-related QOL (SS-QOL) questionnaire, whereas the third phase consisted of two separate studies investigating the overarching research question using both qualitative and quantitative methods. The fourth phase consisted of interpretation and discussion of results (Figure 2). A complete mixed methods synthesis or integration of all results was not possible within this thesis, although complementary aspects of the main results will be interpreted and discussed from different perspectives.

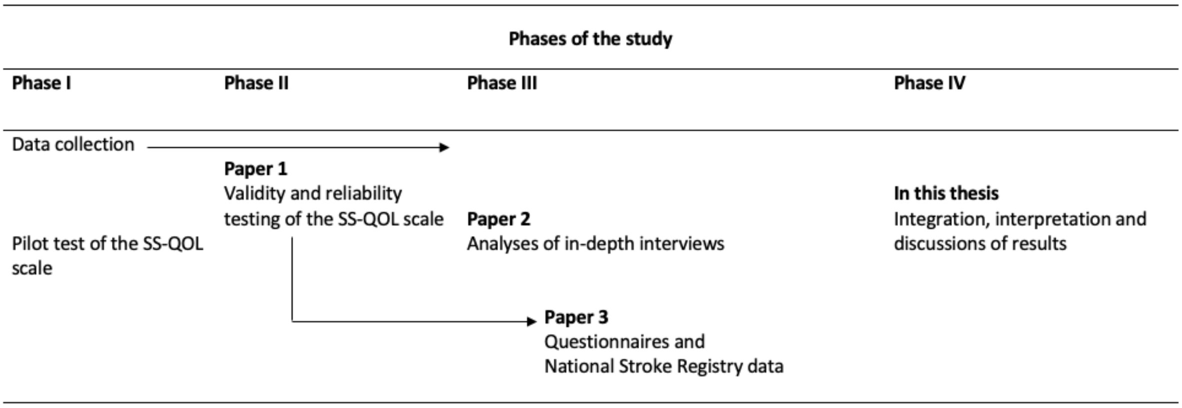


Figure 2 Phases of the study

A fixed (predetermined and planned) and typology-based approach (adaption of a particular design appropriate and useful to the study's purpose and questions) (154) was implemented early in the study. Phase II and III encompassed three different studies with individual designs complementing the research questions for the separate qualitative and the quantitative studies. The validity study in phase II was a prerequisite for the quantitative study in phase III.

Mixed methods notation provides labels and symbols that easily communicate procedures in designs (158). For this thesis, the notation is: (QUAN) → (QUAL + QUAN)

QUAL and QUAN capitalization indicates an emphasis or priority on the qualitative or quantitative data, respectively, whereas lowercase letters would indicate lesser priority or emphasis on the method. The arrow indicates a sequential form of data collection. In this project the first quantitative study had to be proven valid and reliable to proceed with the second quantitative study. The plus sign indicates a convergent integration, with both quantitative and qualitative data collected at the same time. The parentheses indicate that one form of data collection is embedded within another or embedded within a larger design (152, 158, 165).

A parallel mixed design was implemented. The definition of parallel mixed designs in MMR is divergent in the literature, although the following definition (152) was used in this project: 'a family of mixed methods (MM) designs in which mixing occurs in an independent manner either simultaneously or with some lapse. The QUAL and QUAN *strands* are planned and implemented in order to answer related aspects of the same question' (152, p.341, italics in original).

The QUAL and QUAN studies are equal in our design, that is, they are given the same priority. The qualitative and quantitative strands are independent from each other, and each of these strands is presented as separate papers in this thesis. Aspects of qualitative and quantitative results are then interpreted and discussed to develop a more complete understanding of the QOL phenomenon and impact of stroke in the two country-regions. In this thesis a section in the discussion will present this interpretation.

3.2 Study area

3.2.1 The region in North Norway

In Norway, the Coordinating Reform [Samhandlingsreformen] (166) was implemented in 2012. The Reform led to a new municipal Health and Care Services Act (167), and specific responsibilities between hospitals and local health authorities were determined. Key aims included widening the range of health services within municipalities and reducing length-of-stay in hospitals. Other important aims were: increased focus on and enhanced prevention in health; early efforts in interventions; improved cooperation between health services; gathering of specialised, strong professional environments; and bringing health services closer to where people are living. Norwegian municipalities are built up according to what is called 'the generalist principle', implying that every municipality of any size (number of inhabitants) shall offer the same range of services of the same quality (168). At the same time, the municipalities have the freedom to decide the scope of services themselves.

In the North Norwegian region included in this study, individuals with stroke are admitted to one of three stroke units in three different cities University Hospital of North Norway (UNN) Narvik, UNN Harstad, and UNN Tromsø. All stroke units have substantially lower patient-volumes compared to the Danish region. The region of North Norway investigated in this study has special geographical encounters, as the region covers a large area of 30,000 kvm^2, with 870-72,000 inhabitants in 30 municipalities. The geographical conditions challenges some of the aims in the Coordinating Reform and the national clinical guidelines following stroke due to distances, for example, for out-reach teams providing seamless transitions between health care levels, and also availability of local resources in the respective municipalities. Consequently, these factors may affect how rehabilitation services are locally organised and implemented as very few, if any, of the included municipalities had available multidisciplinary teams. In Norway, stroke survivors with needs of long-term and coordinated services have the right of an individual rehabilitation plan, and also a personal coordinator (169). However, these structured organisational plans are rarely implemented according to the intention (170, 171), and have been shown to be implemented weakly both at the system level and at the individual level (168). Although national claims and reforms may have the best intentions, the various reforms and claims might be a challenge due to geographic encounters, lack of local health personnel, and resources to actually fulfil the legislations or guidelines.

3.2.2 Central Denmark Region

In Denmark changes in health legislation (172, 173) have led to municipal reform in 2007 merging municipalities into larger units. Further, the Central Denmark region executed a stroke care reform in 2012 that included specialisation and centralisation of acute stroke care, and moving inpatient rehabilitation care for individuals with mild to moderate stroke symptoms to the municipalities (174). General guidelines for organisation and provision of services included in rehabilitation programs following a stroke are provided by the Danish Health Authority (130, 146).

The Central Denmark region has one centralised stroke unit for a population of 1.3 million inhabitants, and the region deliver centralised neurorehabilitation programs with a large patient volume to achieve specialisation, both at the specialist level and in the municipalities, that is, with health professionals/therapists/multidisciplinary teams with neuro-rehabilitative specialised skills available in the two municipalities included in the study. At the specialist level, the interdisciplinary team is required to document individualised rehabilitation program-plans upon discharge, recommending further rehabilitation provision in the municipality (175), and the municipalities are obliged to follow-up each patient that receives a rehabilitation plan. The two investigated municipalities, Favrskov and Randers, in Central Denmark region have engaged a brain injury coordinator (176) to ensure seamless, patient-oriented practice within each municipality. Additionally, municipalities in Denmark often include job consultants and social workers as part of professional rehabilitation efforts following stroke.

The investigated region in Denmark is 23 times smaller in area than the region in North Norway. Furthermore, the regions in this study differ with regards to treatment centralisation and more structured and often specialised rehabilitation-pathways in Central Denmark. Although the centralisation of stroke care in the Central Denmark region have been described as successful, the stroke care reform has also been critiqued for less successful in achieving integrated rehabilitation care between hospitals and municipalities (174).

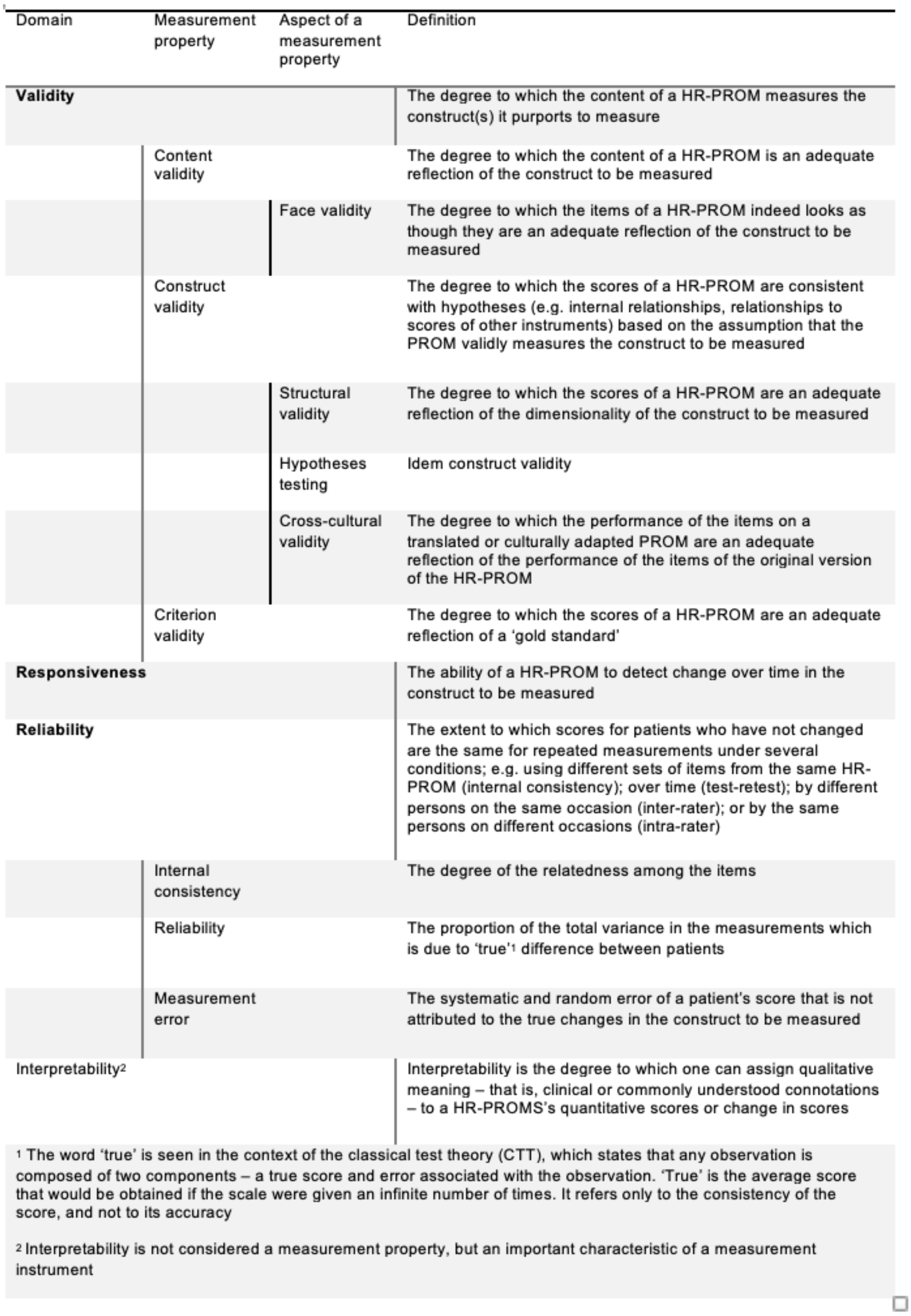
3.3 Validity and reliability of a HRQOL measurement

Evaluations and measurements are important cornerstones in clinical practice and research (177), and both validity and reliability are essential parts of the psychometric properties of a measurement instrument (178). In this study, we chose the Stroke-Specific Quality of Life (SS-QOL) scale, and assessed if the measurement actually measured the intended concept or construct (validity), and provided stable or consistent responses (reliability) (177, 178). Hence, we wished to determine how the measure compared with similar instruments (177), and choose additional adequate instruments for this purpose.

The first part of this study involved validity and reliability testing of a health-related quality of life (HRQOL) measure, the SS-QOL scale, for adaptation in the Norwegian language. We chose this precise scale because our Danish collaborators had used it in related research projects and the SS-QOL was a comprehensive scale, embracing several significant factors in stroke survivors' lives that convey HRQOL. However, the scale had never been adapted for use in the Norwegian language and population, and this was a prerequisite for generating specific outcome of HRQOL in both country-regions. Translations and a pilot test were performed.

Since we were evaluating aspects of QOL through a patient-reported outcome measure (PROM), we chose to follow the consensus-based standards for the selection of health measurement instruments, the COSMIN guidelines (179, 180). The COSMIN initiative was founded in 2005 on the background of 'a lack of clarity in the literature about terminology and definitions of measurement properties, a lack of evidence on the measurement properties of many outcome measurement instruments, and inconsistency in methods used to determine these measurement properties' (181, webpage). The COSMIN-group developed consensus-based taxonomy and standards for assessing the quality of studies on measurement properties (181). Various forms of validity and reliability specifically regarding health-related patient reported outcome measures (HR-PROMs) exist (179, 182-184), and they are presented in Table 2.

Table 2 Validity and reliability in health-related patient reported outcome measure (HR-PROM)



Domain	Measurement property	Aspect of a measurement property	Definition
Validity			The degree to which the content of a HR-PROM measures the construct(s) it purports to measure
	Content validity		The degree to which the content of a HR-PROM is an adequate reflection of the construct to be measured
		Face validity	The degree to which the items of a HR-PROM indeed looks as though they are an adequate reflection of the construct to be measured
	Construct validity		The degree to which the scores of a HR-PROM are consistent with hypotheses (e.g. internal relationships, relationships to scores of other instruments) based on the assumption that the PROM validly measures the construct to be measured
		Structural validity	The degree to which the scores of a HR-PROM are an adequate reflection of the dimensionality of the construct to be measured
		Hypotheses testing	Idem construct validity
		Cross-cultural validity	The degree to which the performance of the items on a translated or culturally adapted PROM are an adequate reflection of the performance of the items of the original version of the HR-PROM
	Criterion validity		The degree to which the scores of a HR-PROM are an adequate reflection of a 'gold standard'
Responsiveness			The ability of a HR-PROM to detect change over time in the construct to be measured
Reliability			The extent to which scores for patients who have not changed are the same for repeated measurements under several conditions; e.g. using different sets of items from the same HR-PROM (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater); or by the same persons on different occasions (intra-rater)
	Internal consistency		The degree of the relatedness among the items
	Reliability		The proportion of the total variance in the measurements which is due to 'true'[1] difference between patients
	Measurement error		The systematic and random error of a patient's score that is not attributed to the true changes in the construct to be measured
Interpretability[2]			Interpretability is the degree to which one can assign qualitative meaning – that is, clinical or commonly understood connotations – to a HR-PROMS's quantitative scores or change in scores

[1] The word 'true' is seen in the context of the classical test theory (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

[2] Interpretability is not considered a measurement property, but an important characteristic of a measurement instrument

Reprinted text with minimal adaptions from the Journal of Clinical Epidemiology, Volume 63/Issue 7, Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, Bouter LM, de Wet HC. *The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes,* p. 743. Copyright (2010), with permission from Elsevier.

3.3.1 Translation and pilot test

Permission to use the SS-QOL scale was obtained from the developer (185) before translation and further pilot testing of psychometric properties.

Standard guidelines were followed for the forward and backward translation process and pilot testing of the SS-QOL questionnaire (186). In addition to the translation procedures described in paper I, three Danish people, working as health professionals in Norway translated the Norwegian version of the SS-QOL back to Danish (blinded from both the Danish and the English versions). This was done as a procedure to ensure that meanings in both languages coincided.

The following modifications was based on the different back translations generated:

1) The response category for 'personality' in the additional psychometric section of the questionnaire was transformed to obtain a more appropriate response in the Norwegian language. The Danish version of the questionnaire had a similar alteration (187). The original English response options for 'my personality is….' Were as follows: 'A lot worse than before my stroke', 'somewhat worse than before my stroke', 'a little worse than before my stroke', and 'the same as before my stroke'. The transformation to Norwegian were: 'Significantly changed', 'somewhat changed', 'slightly changed', and 'unchanged'.
2) Explanatory examples within the items were excluded in the Norwegian version, e.g. 'did you have trouble eating, for example cutting food or swallowing', removing the last part of the sentence. This was also similar to the Danish version (187) of the SS-QOL scale. The explanatory examples within the items were removed since they were considered superfluous and unnecessary to answer the questions.

The forward- and back-translation processes confirmed a satisfactory match in semantic meaning between the original and the back-translated SS-QOL items. After translations and final modifications had been done, we asked four Norwegian stroke survivors to complete the questionnaire, and to evaluate the instructions, items, and response categories to ensure a fully comprehensible translation. No additional changes were made after the pilot testing.

3.4 Participants and data collection

Participants paper I and III

Only Norwegian participants were included in paper I.

Norwegian participants were included if they were 1) diagnosed with a first-time stroke using the WHO International Classification of Diseases, version 10 (ICD.10) (I.61 and I.63), 2) admitted to one of three stroke units at the UNN located in either a) Narvik, b) Harstad, or c) Tromsø, 3) ≥18 years old, 4) living in one of 30 municipalities in Troms County in the Northern Region of Norway with a total of 190,000 citizens, and 5) in the period between March 15, 2014 and December 31, 2015.

Danish participants were included if they were 1) diagnosed with a first-time stroke (same criteria as indicated above), 2) admitted to the stroke unit at Aarhus University Hospital (AUH), 3) ≥18 years old, 4) living in either Favrskov or Randers municipalities with respectively 48,000 and 61,000 citizens located in the Central Region of Denmark. The inclusion period in Denmark was from June 1, 2014 to December 31, 2015.

Both transient ischaemic attack and subarachnoid haemorrhage (SAH) are included in the Danish stroke registry (188), but in this study individuals with stroke related to brain malignancy, SAH, or traumatic brain injury were excluded from both countries. Proxy-responders referred to patients, caregivers, or health personnel completing only the demographic section of the questionnaire and were also excluded from this study. The one-year follow-up in both countries terminated at the end of February, 2017.

Data collection paper I and III

Recruitment of participants and data collection were initiated after approval from the Regional Committee for Medical and Health Research Ethics for Northern Norway (Appendix 1 and 2), and the Danish Data Protection Agency.

Paper I

Written consent (Appendix 3) was obtained prior to initiation of the study with Norwegian participants from the three stroke units in UNN, located at either the city of Narvik, Harstad, or Tromsø. Stroke survivors were informed and asked to provide consent by nurses or health professionals responsible for updating the information in the National Norwegian Stroke Register. Three months post-stroke, a questionnaire package was mailed to the 161 participants home addresses (Appendix 4). A sub-sample of 40 individuals provided consent to participate in a test-retest study at 12 months post-stroke (Appendix 5), as we assumed more stable responses in HRQOL functioning scores. We re-administered the questionnaires seven days from the date of the first administration to the 36 consenters that responded within the desired timeframe.

Paper III

Norway: Nurses in stroke units or health professionals informed potential participants about the study and asked for written consent either in person or by telephone. Acute phase data from the National Norwegian Stroke Registry (Appendix 6) was retrieved after the data collection of questionnaires.

Denmark: A health professional retrieved information directly from the National Stroke Registry on patients with stroke who were living in the respective municipalities. Potential participants were contacted by telephone at three months post-stroke. Those who agreed to answer to interview-questions on rehabilitation (three months) and/or complete the questionnaires (three/12 months) were enrolled in the study.

All potential participants from both regions received a posted questionnaire package one-year post-stroke. Additionally, three months post-stroke, information about rehabilitation services was obtained by telephone (both regions) or in connection with an outpatient visit (Norway). Collected information was based on follow-up registrations at three months in the National Norwegian Stroke Registry (Appendix 7), and adjusted for use in Denmark (Appendix 8) for this study.

A flowchart illustrating the inclusion process of participants in study I and III is presented in Figure 3.

Participants paper II

The participants consisted of a strategic selection of 11 identified stroke survivors, living in the predefined geographical areas of North Norway and Central Denmark. Included participants lived in 5 (of a total 30) municipalities in Norway, and 2 (of a total 2) municipalities in Denmark. Adult participants were eligible for this study if they had a clinically confirmed diagnosis of ischaemic or haemorrhagic stroke and had physical and/or cognitive impairments requiring further rehabilitation after discharge from a stroke unit. Additionally, they had to live active independent lives prior to the stroke event.

Data collection paper II

Eligible stroke survivors were recruited and asked to provide consent (Appendix 9) by health personnel at local in-patient rehabilitation wards in both country-regions. The recruitment period was from spring 2014 to spring 2015, with a one-year follow-up. The patients were strategically chosen in line with the inclusion criteria. Semi-structured interviews were conducted by co-authors (S.M., C.A., L.Aa., H.P) shortly before discharge from the hospital and three and 12 months after stroke onset. This study reports results from the interviews conducted approximately one year following stroke. The interviews were conducted in the participants’ homes or workplaces and ranged from 60-90 minutes in duration. All interviews were audiotape-recorded with the participants’ permission, and thereafter transcribed verbatim with identifying data removed.

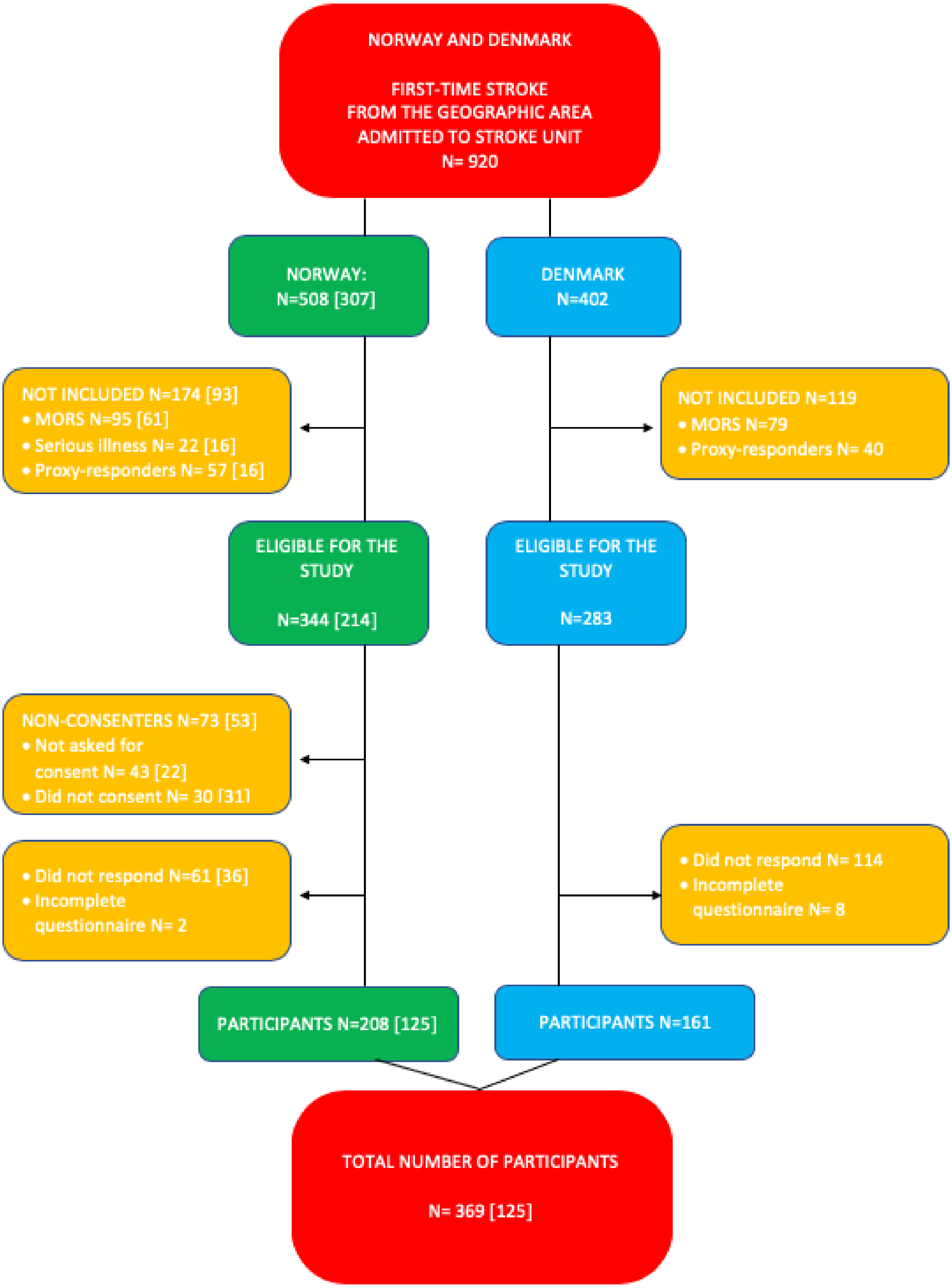


Figure 3 Flowchart of individuals with stroke. Participants in paper 1 are presented in [ ]

3.4.1 Dropout analyses papers I and III

Paper I

In the group non-consenters (n=53) from Figure 3 (flowchart), 31 patients did not provide consent, 10 patients were mistakenly not asked for consent, and 12 patients did not receive the questionnaire due to administrative errors. The age of the non-consenters was higher ($p < .05$) (M_{age} 75 years, median 78 years, and range 41-95) than the participants (Table 3), but the magnitude of the difference was low. Due to Norwegian ethical rules, comparisons between participants and non-consenters were possible for age and gender only.

Individuals with stroke who initially consented but did not respond (n=36) were significantly older and had a significant higher percentage of institutionalized patients. This group also had a significant higher proportion of severe disability measured by the modified Rankin Scale (mRS) and significantly more single or widowed individuals. Gender and stroke subtype were similar in both groups (Table 3).

Table 3. Socio-demographic and stroke characteristics of non-responders and participants

NORWAY	Non-responders **N=36**	Participants **N=125**	P-values’
Age, mean (*SD*)	75 (13.6)	70.5 (13.1)	<.05
Gender, n (%)			
Female	16 (44)	48 (38)	.34
Male	20 (56)	77 (62)	
Stroke subtype, n (%)			
Ischaemic	31 (86)	113 (90)	.33
Haemorrhagic	5 (14)	12 (10)	
Marital status, n (%)			
Married/cohabitant	16 (45)	80 (64)	
Widowed/single	20 (55)	45 (36)	<.05
Education, n (%)			
< 10 years	-	60 (48)	
≥ 10	-	62 (50)	-
Unknown	-	3 (2)	
Living conditions at 3 months, n (%)			
Home, without assistance	12 (33)	92 (73)	
Home, with assistance	14 (39)	23 (19)	<.01[a)]
Institution/residence for elderly	10 (28)	10 (8)	
Work status at 3 months, n (%)			
Student/working fulltime or part-time	3 (8)	23 (18)	
Retired/sick-leave	33 (92)	102 (82)	.77
Modified Rankin Scale at 3 months, n (%)			
0 – 1 no symptoms or no significant disability	15 (42)	84 (67)	
2 – 3 slight or moderate disability	16 (44)	33 (26)	<.05[b)]
4 – 5 severe disability	5 (14)	8 (7)	

[a)] Significantly more responders than non-responders lived at home without assistance vs. at home with assistance/in institution three months post stroke.

[b)] Wilcoxon signed rank test

Paper III

Stroke survivors not-included in study III were divided into regional dropout analyses due to different ethical guidelines in the two countries and thereby different data collection procedures. For comparisons of non-consenters and participants we had data for age and gender only in Norway, whereas we could use all available data from the non-participating subjects in Denmark. Table 4 and Table 5 illustrate dropout analyses in the region of North Norway, whereas Table 6 presents dropout analyses for the region in Central Denmark.

Table 4. Norway. Demographics of non-consenters and participants

NORWAY	Non-consenters **N=73**	Participants **N=208**	P-values
Age, mean (*SD*)	73.6 (13.5)	69.8 (11.3)	.035
Gender, n (%)			
Female	46 (63)	88 (43)	.002
Male	27 (37)	120 (57)	

Table 5. Norway. Demographics and stroke characteristics of non-responders and participants

NORWAY	Non-responders **N=63**	Participants **N=208**	P-values'
Age, mean (*SD*)	70.2 (15.9)	69.8 (11.3)	.862
Gender, n (%)			
Female	26 (41)	88 (43)	.884
Male	37 (59)	120 (57)	
Stroke subtype, n (%)			
Ischemic	55 (87)	191 (92)	.647
Haemorrhagic	8 (13)	17 (9)	
Scandinavian Stroke Scale, acute, median [IQR]	46 [10]	47 [11]	.012
Stroke unit length-of-stay, median [IQR]	7 [8]	4 [4]	.001

Table 6. Denmark. Demographics and stroke characteristics of non-responders and participants

DENMARK	Non-responders **N=122**	Participants **N=161**	P-values'
Age, mean (*SD*)	69.4 (12.7)	66.7(11.4)	.066
Gender, n (%)			
Female	56 (46)	65 (40)	.352
Male	66 (54)	96 (60)	
Stroke subtype, n (%)			
Ischemic	107 (12)	145 (90)	.529
Haemorrhagic	15 (88)	16 (10)	
Scandinavian Stroke Scale, acute, median [IQR]	50 [18]	52 [13]	.003
Stroke unit length-of-stay, median [IQR]	2 [2]	2 [2]	.798

3.5 Descriptions of variables and questionnaires

3.5.1 Variables

Variables in paper I and III consisted of sociodemographic variables, stroke characteristics, rehabilitation data, single items, as well as questionnaires.

The aim of stroke registries is to collect data on the individual patient, as well as key processes of care, mainly covering the acute phase. In the preparation phase of the study, relevant and comparable variables were identified in the national stroke registries of both countries. Final included variables are found in Table 7.

Demographic variables

Paper I

Marital status, education, and work status were collected from the questionnaires. Information on age, gender, living situation, stroke characteristics, and the modified Rankin Scale (mRS) was obtained from stroke registry data.

Paper III

At baseline, data on age, gender, stroke subtype, acute treatment, and length-of-stay were obtained from both countries' National Stroke Registries. The questionnaires supplemented information for marital status (married/cohabitant or single), pre-stroke self-care dependence (living with or without assistance pre-stroke), and work status (working/studying prior to stroke).

Table 7 Variables used in papers I and III

Variables	Paper I	Paper III
Sociodemographic and stroke characteristics		
Age at time of stroke	X	X
Gender	X	X
Marital status	X	X
Education level	X	
Self-care dependency at 3 months	X	
Self-care dependency at 12 months		X
Work status at 3 months	X	
Work status at 12 months		X
Stroke subtype	X	X
Stroke unit length-of-stay		X
Thrombolysis		X
Thrombectomy		X
Single items		
“Mobility” (Norwegian Stroke Register)	X	
“Getting dressed” (Norwegian Stroke Register)	X	
“Problems with vision” (Norwegian Stroke Register)	X	
“Problems speaking” (Norwegian Stroke Register)	X	
“Daily activities” (QOLIBRI-OS)	X	
“Personal and social life” (QOLIBRI-OS)	X	
“Concentrate/remember/thinking” (QOLIBRI-OS)	X	
“Feelings/emotional state” (QOLIBRI-OS)	X	
Scales		
Modified Rankin Scale at 3 months	X	
Stroke-Specific Quality of Life (SS-QOL) scale	X	X
Quality of Life After Brain Injury, Overall Scale (QOLIBRI-OS)	X	
EuroQol Quality of Life Scale - 5D (EQ-5D)	X	
EuroQol Visual Analogue Scale (EQ VAS)	X	
Hospital Anxiety and Depression Scale (HADS)	X	X
Scandinavian Stroke Scale (SSS)		X
Scale domains		
“Gait” (EQ-5D)	X	
“Usual activities” (EQ-5D)	X	
Depression (HADS)	X	X
Anxiety (HADS)		X
“Personal hygiene” (EQ-5D)	X	
Rehabilitation data		
In-patient rehabilitation		X
Community-based rehabilitation		X
No follow-up after stroke unit		X

3.5.2 Measurements

The Stroke-Specific Quality of Life (SS-QOL) scale

The main outcome measure to assess the perceived impact of stroke for this study was the SS-QOL scale, version 2.0, by Williams et al. (185). The scale was developed through interviews, pilot testing, and evaluations of stroke survivors. The SS-QOL scale consists of 49 items covering 12 domains: mobility, energy, upper extremity function, work and productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality. Each domain is measured by three to six items using a 5-point (1-5) Likert scale (higher scores indicate better function). An average non-weighted raw score for each domain can be generated, enabling comparison of the relative level of each domain and the total score. Although the overall SS-QOL summary score is often used as the primary outcome, the domain scores are helpful for identifying specific areas that are affected by stroke or that improve the most or least over time (185). The validity of the SS-QOL has been examined when administered by telephone (187, 189), self-report and mail (190), and with proxy responders (191, 192).

The SS-QOL scale was previously used in Denmark (190), and validated for the Norwegian language in this study (193). Reliability for the SS-QOL scale has been documented by several studies, with acceptable and good internal consistency of the domains (Cronbach's alpha= .79-.93, Norway, and α=.81-.94 Denmark). Test-retest stability of the SS-QOL scale has similarly been documented as generally good (Spearman's rho=.67-.94, Norway, and r=0.65-0.99, Denmark) (190, 193). The SS-QOL items have suitable agreement with the categories of the International Classification of Functioning, Disability and Health (ICF) (194).

The SS-QOL scale has additional 13 questions of perceived change post-stroke compared to pre-stroke. Each question relates to the 12 domains of SS-QOL, and one additional question relates to change in overall experience of QOL compared to pre-stroke. These 13 questions are not published as part of paper III, but results will be presented in this thesis.

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a widely used brief screening inventory for self-reported symptoms of anxiety and depression that can be used to reliably and validly detect these mental health states (195, 196). Respondents are asked to fill out a 14-item scale that consisted of 7 questions for anxiety symptoms, and 7 questions for depressive symptoms. The item response scale ranges from 0-3 (higher is worse), and subscale sum scores range from 0-21. The total HADS score (range 0-42) may be considered a global measure of psychological and emotional distress (197). A cut-off score of ≥8 indicates a possible diagnosis of anxiety and depression (198). The scale was validated in Norwegian with good psychometric qualities (199), and is appropriate for a wide age span from youth to old age (200). The HADS has previously been used post-stroke (201, 202).

The EuroQol Quality of Life Scale (EQ-5D)

The EuroQol five dimensions questionnaire (EQ-5D) is one of the most commonly used generic HRQOL measures. The EQ-5D has five domains, which evaluate mobility, self-care, ability to perform daily activities, pain/discomfort, and anxiety/depression (72, 203). Each dimension is self-rated by the individual into one of three levels of disability (severe, moderate or none) (203). Construct validation in this study was performed on descriptions of the five individual dimensions and not on the preference-based index that can be derived from this measure, and this is in accordance with the literature (204, 205). The EQ-5D total score was used to test the convergent validity of the total SS-QOL scale score. The EQ-5D has been evaluated extensively in different cultures and languages, and is short and easy to use (72).

The EuroQol Visual Analogue Scale (EQ-VAS)

The EuroQol Visual Analogue Scale (EQ-VAS) is a self-rated health status assessment where the individuals rate their own current overall health from 0-100 (from worst to best imaginable health) (203, 206). The VAS-scale can be used to monitor change over time and has been shown to be responsive to the symptoms and severities indicated by condition-specific instruments (207).

The Quality of Life After Brain Injury, Overall Scale (QOLIBRI-OS)

The Quality of life after Brain Injury, Overall scale (QOLIBRI-OS) includes six items that assess the degree of overall satisfaction with physical condition, cognition, emotions, ability to perform daily activities, personal and social life, and current situation and future prospects. Each item is provided by a Likert scale of five response categories (1-5); 1) not at all, 2) slightly, 3) moderately, 4) quit, and 5) very (208). Correspondingly, the sum score range is 6-30. The sum of all items can be arithmetically converted to a percentage scale(208). The QOLIBRI-OS has recently been validated for individuals with stroke (73), and has demonstrated good internal consistency with Cronbach's α value of 0.93 in persons with ischemic or haemorrhagic stroke(73), α=0.86 after traumatic brain injury (208), and α=0.88 in persons with subarachnoid haemorrhage (209).

Modified Rankin Scale (mRS)

The modified Rankin Scale (mRS) is a 6 item, global outcome scale for patients' post-stroke, and is used to categorize the level of functional independence or disability in activities of daily living (210). The mRS is one of the most commonly used functional measures in stroke trials, and is often a primary or co-primary outcome in recent large-scale stroke trials (211).

3.6 Interviews and analyses

Qualitative research is situated in an interpretative paradigm where notions of human experiences in context are recognized from a subjective position (212). Through qualitative in-depth interviews, the phenomenon of QOL can provide insight through contextualization (213, 214). The method allows for proximity to the field, so that the researcher can gain depth, highlight peculiarities, look at different contexts, describe patterns, and convey understandings derived from the participants (212, 215, 216). Semi-structured in-depth interviews were chosen as suitable for discovering nuances and diversity in the phenomenon of QOL (217, 218). The interview guide (Appendix 10) was developed through collaboration among authors and included topics on experiences and reflections regarding perceptions of life and the recovery process. The basic purpose was to 'find the essence' (219) of QOL through diverse experiences, and to explore similar or dissimilar experiences of QOL in the two country-regions.

The interviews resulted in rich descriptive data that was systematically coded and categorized in the software program NVivo 11. Analyses were conducted as an iterative process inspired by hermeneutic epistemology (220). The interpretation of text with transformations back into meaning included alterations between deductive codes and categorizations, and continuously checking these interpretations against the transcripts as raw material and the literature. Hence, interpretations were continuously developed through the hermeneutic circle with multiple stages of understanding, and in the context of both deductive parts and the entire text. The interaction between the interpreter and the object of interpretation, as well as the fact that we all understand differently is acknowledged by Gadamer (220, 221). However, the hermeneutic circle is a means to reach understanding by modifying our own anticipations and expectations through the multiple stages of interpretation (221). This was addressed through systematic reading of interviews, and repeated analytic discussions among the research group.

The transcripts were read fully several times prior to reduction of the data, and then the systematic coding was performed. Systematic text condensation (STC) (222) was used as inspiration for the inductive analytic strategy in this study. STC is a pragmatic procedure inspired by Giorgi's (223) psychological phenomenological analysis and involves analytic shifts between decontextualisation and recontextualisation of data. According to Malterud, this analytical method offers the researcher a process of intersubjectivity, reflexivity, and feasibility while maintaining methodological rigour (222, p.795). I developed a matrix (Table II, paper II) with coding, meaning units, condensates, categories and themes, as well as a reflexive journal in the analytic process. The coding was discussed with the last author to reach a consensus of subgroup priority. New interpretations of descriptions of patterns and concepts were generated through synthesizing the contents of the condensates, as well as through literature and research of the ‘embodied self’ (224, 225).

3.7 Statistics and data analyses

The Statistical Package of Social Sciences (SPSS) software (IBM Corporation, versions 23 and 26), were used for all statistical analyses in papers I and III, respectively. Occasional missing items were replaced with the mean of the subscale the item was part of according to defined criteria presented in the papers. The distributional properties (e.g. skewness and kurtosis) of the SS-QOL subscales were examined by visual inspections and with normality plots with tests (e.g. Q-Q plots). Descriptive characteristics of the study population are presented as mean (*M*) and standard deviations (*SDs*) for continuous variables and number and percentages for categorical variables. Statistical differences between groups were tested by independent sample t-tests for continuous variables and by the χ^2 test for categorical variables, or the Fisher's exact test in case of few cases in a subgroup. Non-normally distributed data were examined with non-parametric statistical analyses, for example, the Mann-Whitney test or Wilcoxon signed-rank test, to compare distributions in two conditions with different entities (226).

Reliability tests

Cronbach's alpha (α) values were estimated as an indication of the internal consistency of the SS-QOL total and domain scores. A rule of thumb requires the Cronbach's α-value to surpass ≥ 0.70 (177) to conclude that the items constituting a scale are satisfactorily highly correlated and precise as a measure of the construct in question.

The test-retest stability of the SS-QOL scale (paper I) was examined by two means; 1) Spearman's ρ, to quantify the magnitude of the correlation between the scores on the first and second administration, which should surpass 0.7 (227, 228), and 2) intra-class correlation coefficients (ICCs), to assess agreement in the use of the response scale based on a two-way mixed model. Coefficients were estimated for both $\mathrm{ICC}_{\mathrm{consistency}}$ and $\mathrm{ICC}_{\mathrm{agreement}}$. The latter (agreement) is most relevant for test-retest purposes as it indicates the degree of absolute agreement between two measurement occasions, i.e., the degree of equality in mean values in addition to the consistency or correlations between scores. However, if consistency estimates deviate markedly from absolute estimates, relative agreement may still be good despite poorer absolute agreement. That could indicate instabilities in the interpretation of the response scale continuum, and for that reason both are reported (177). The ICC should also surpass 0.7 (227).

Standard error of measurement

Standard error of measurement (SEM) is an index of the size of measurement error in a measured variable. Score differences greater than the score interval related to measurement error alone are thus due to real changes in the underlying construct rather than being caused by measurement errors (226, 229). A distribution-based method was used to calculate the SEM, and values for each domain were generated to indicate the required magnitudes of detectable change. The SEM was estimated based on the Cronbach's alpha (r_{xx}) of the scale, as well as its SD (229):

$$SEM = SD\sqrt{1 - r_{xx}}$$

The calculated number amounts to one SEM, thus, indicating how much of the observed variance in measured score (quantified as one standard deviation) amounts to measurement error variance. A lower SEM thus indicates a more precise measurement.

Validity

Content validity involves a subjective critical evaluation of whether the items of a measurement reflects a representative selection of indicators measuring the intended construct of HRQOL. The content validity of the SS-QOL scale has been well-documented by others (185, 190, 192), and we focused on the construct and criterion validity of the SS-QOL scale.

In accordance with literature (177) and the COSMIN guidelines (230), we examined if the observed correlations between scales were in line with the hypothesised magnitudes and directions between the SS-QOL scale and criterion-related measures, both in terms of convergent validity (positive correlations) and divergent validity (negative correlations). As the criterion-related response scales were of an ordinal nature and some criterion-related variables were based on single item scores, an ordinal rank correlation metric was preferred (226). Correlation coefficients (Spearman's ρ) for these analyses were: $\pm$ 0.1 = small, $\pm$ 0.3 = medium, $\pm$ 0.5 = large (231). Construct validity was considered supported if ≥ 75% of the observed correlations corresponded with the hypothesised correlations (227).

Principal component analysis

The SS-QOL domain scores were moderately to strongly inter-correlated (paper III); hence, and a principal component analysis (PCA) was performed to determine whether the 12 domains clustered and could be summarized in more general components. As we expected high correlations also among the calculated component scores, the component loadings were rotated using an oblique method, i.e., promax (226) with kappa=4. The PCA extracted two general components of the SS-QOL scale. As two of the domain scores were poorly accounted for by these two general components, i.e., vision and language, they were excluded. These should be interpreted separately from the two general components.

Regression analysis

Bootstrapping was performed both for the t-tests and for the multiple regression analyses (paper III) to obtain confidence intervals (CI) more robust from deviations in the SS-QOL scale from the normal sampling distribution (226). Empirical bootstrapping randomly selects with replacement a smaller set of cases from the original sample in order to construct CIs based on all the sampled cases that mimic the sampling distribution of the population. A number of n=5000 re-samplings were used. Since bootstrapping does not provide standardised beta coefficients, all variables were transformed to z-scores (*M*=0, *SD*=1) which makes coefficients standardised (226).

3.8 Ethics

The study was performed in accordance with the Declaration of Helsinki for research ethics (232). The Regional Committee for Medical and Health Research Ethics for Northern Norway approved the study (Ref.no 2013/1461). In Denmark, the qualitative paper II (record no. 1-16-02-66-14) and the quantitative paper III (record no. 1-16-02-363-14) study was approved by the Danish Data Protection Agency.

All invited stroke survivors or caregivers had the opportunity to contact a person in the research team if they needed more information about the study or had questions. A number of 15 individuals contacted us to express that they did not want to participate in the study, and one individual contacted us due to a change in diagnosis. A few contacted us to ask for more information about the study, and one withdrew from the study after responding to the 3-months questionnaire package.

Adequate and secure data handling are of the utmost importance for ethics and to maintain the participants' confidence in research participation. Informed consent and questionnaires were scanned and stored on a secure data server as recommended by the local data protection officer at the University Hospital of North Norway (UNN). The quantitative data have been handled and stored de-identified with a unique admission-key according to the procedures for secure archiving of research data at the UNN. Qualitative data were transcribed with identifying data removed and stored in the localhost NVivo program.

The research involved adult stroke survivors capable of giving consent. Nevertheless, stroke survivors are a vulnerable group and several individuals might struggle with cognitive, emotional, or mental health impairments. This required understandable divulgation with standardised information about the research project provided at the same time as the request to signing of the consent form. Additionally, all participants had the opportunity to contact anyone in the research team to ask for more information or withdraw from the study during the data collection period.

4 Results

4.1 Summary of paper I

The main aim of this study was to examine the validity and reliability of a Norwegian version of the 12-domain Stroke-Specific Quality of Life (SS-QOL) scale.

The Norwegian version revealed no major changes in back translations. A few exceptions were resolved through consensus discussions, and resulted in minor adjustments i.e., revising the layout and removing explanatory examples.

The degree of missing data in the SS-QOL scale was low (1.4%), and data were replaced by consulting participants or by the domain mean values. The total score of the SS-QOL scale had an acceptably low ceiling effect (8.8%), whereas all the domain scores had ceiling effects that surpassed the 15% limit. The domains self-care, vision, and language had considerable ceiling effects (above 50%). Conversely, floor effects were absent.

Cronbach's alpha (α) coefficients showed acceptable and good internal consistency for the domains (α=0.79-0.93) and for the SS-QOL total (α=0.97). The item-to-subscale correlation coefficients supported convergent validity (0.48-0.87), and the item-total correlations ranged between 0.44-0.83 for all 49 items.

The test-retest reliability indicated stability for most domains, however the vision domain had lower Spearman's correlation (rho = 0.35) compared to the other domains. ICC values were excellent for all domains and estimates between $\text{ICC}_{\text{agreement}}$ and $\text{ICC}_{\text{consistency}}$ were minor. The ICC estimates indicated that participants interpreted the response scale similarly at both measurement occasions. Hypothesis correlations of criterion-related measures supported the construct validity of the SS-QOL scale.

4.2 Summary of paper II

This study aimed to explore QOL during the first year of recovery after stroke in defined geographic regions in North Norway and Central Denmark with overall similar health systems, but differences in organisation of subacute rehabilitation services.

Stroke was experienced as a discontinuity in life, which essentially changed the story and conception of who the participants were. We found that QOL as experienced reflected a reconstruction of the embodied self, a process related to different phases of self-reconstruction and also closely related to important functions and environmental or external factors. Three intertwined and negotiating processes of self-reconstruction were identified: a familiar self, an unfamiliar self, and recovery of self. The participants described fluctuations in and between these processes throughout the recovery phase, although the ultimate aim seemed to be reaching a familiarity in all aspects in live (a familiar self).

Reconstruction of the embodied self and QOL were also framed as an ongoing process of '*being, doing, belonging, and becoming'* in this study. These aspects conceptualise 'being' as humans and may provide an understanding concerning essential human desires and possibilities significant to QOL. Tiredness, activities, social relations, and presence and continuity in follow-up from professionals were all important findings in this study. These findings were linked to the aspects of *being, doing, belonging and becoming,* demonstrating a connectedness between functions, relations, professional support and experiences of QOL. Enriching social relations, resumption of valued activities, successful return to work, continuity and presence in professional support during the recovery process positively influenced reconstruction of the embodied self and QOL. Fatigue and sustained reduced function, negatively influenced the perceived QOL.

The study demonstrated different aspects of the embodied self and variations in reconstructing the embodied self one-year post-stroke. Although the recovery processes and contexts were different, the self-reconstruction process emerged as important for QOL in both country-regions. The variances in professional support revealed differences in continuity and sustained support between the region in Central Denmark (continuity and more seamless rehabilitation-pathways) and the region in North Norway (descriptions of discontinuity and unmet needs in professional follow-up) and how such differences affected reconstruction of the embodied self.

4.3 Summary of paper III

This study's aims were to examine and compare stroke-specific HRQOL at one-year post-stroke in two Scandinavian country-regions with differences in subacute rehabilitation services, and to reveal whether organisational factors or individual factors impacted on outcome. The primary outcome was the SS-QOL scale at one-year post-stroke.

A consecutive sample of 369 first-ever stroke survivors in North Norway (n=208) and Central Denmark (n=161) were enrolled in the study (42% females, mean age 68 [*SD* 11.4] years). The North Norwegian participants were older than participants from Central Denmark (M_{age}= 69.8 vs 66.7years, respectively; *p*<.05), had higher stroke severity (*p*<.01), and longer stroke unit stays (*p*<.001). Most participants had mild (70%) and moderate (26%) initial stroke severity. There was indication of more inpatient rehabilitation in North Norway, whereas participants from Central Denmark received municipality-based rehabilitation services either at home or in a daycentre to a higher degree.

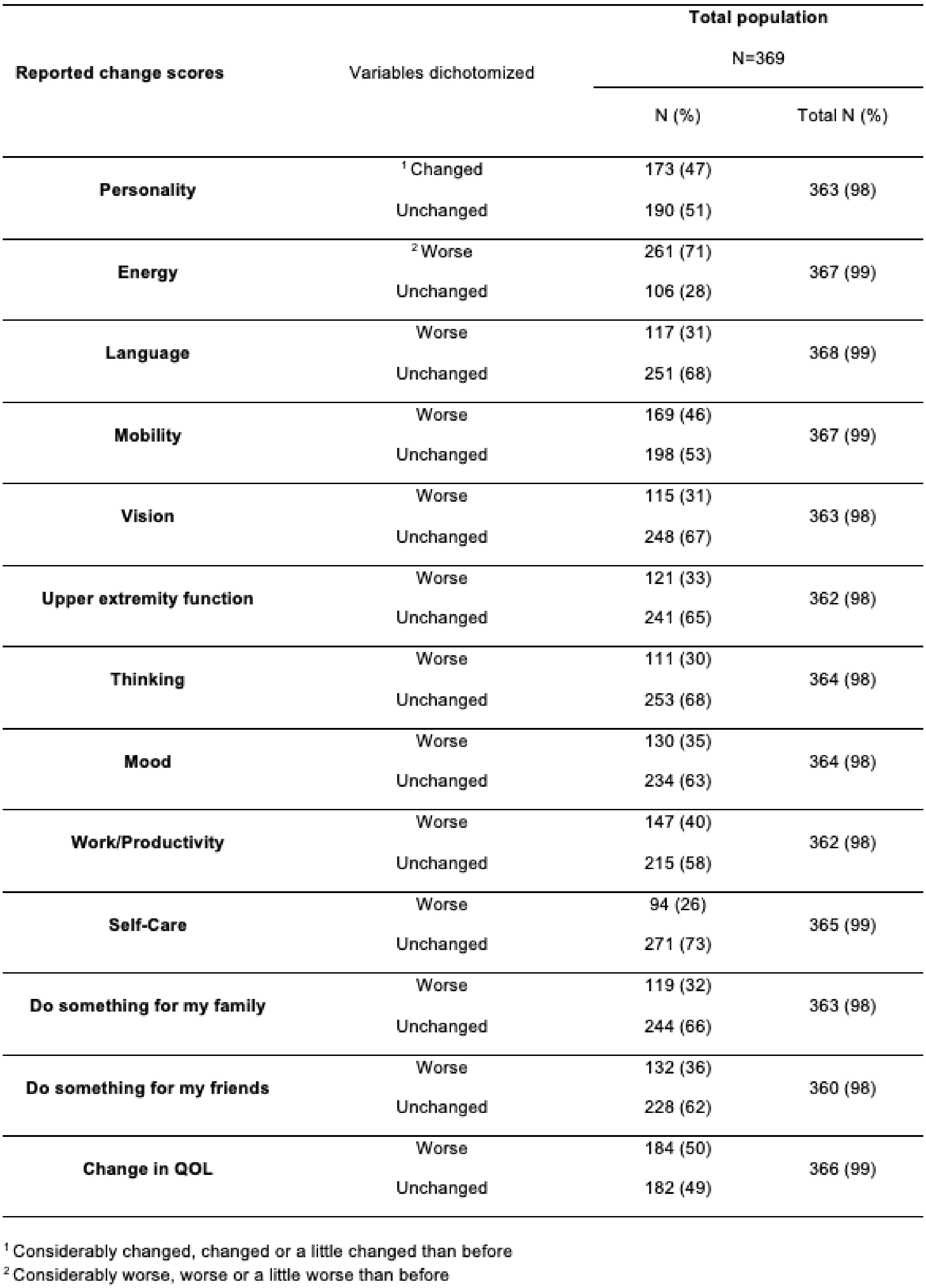
A statistically significant difference between the country-regions emerged for the total SS-QOL scale and five of the SS-QOL domains: energy, family roles, language, thinking and personality. The statistical magnitude for these differences was minor (small Cohen's *d*) with participants from the North Norwegian region reporting slightly better functioning than patients in Denmark. Both cohorts reported more problems with cognitive, social and emotional functioning compared to physical functioning. A principal component analysis of the 12 SS-QOL subscales extracted two components. Hence, the 12 SS-QOL subscales may, as an alternative, be summarized into two general scales that we labelled physical health (PH) and cognitive-social-mental (CSM) components.

Between-country multiple regression analyses for the SS-QOL total scale and the PH and CSM components showed that participants in the Danish region reported more functional problems compared to participants from the North Norwegian region. The analysis maintained statistical significance for the country difference variable after adjustments for predefined covariates. This finding did not confirm our expectation of better self-reported HRQOL in the Central Denmark region. Younger age, pre-stroke self-care independence, and less initial stroke severity were significantly associated with better outcome. Additionally, anxiety and depression scores accounted substantially for the individuals SS-QOL scores. Hence, SS-QOL scores one-year post-stroke were strongly explained by the individual factors (e.g., pre-stroke dependency and mental health), and weakly explained by country differences in the organisation of the subacute rehabilitation services.

4.4 Additional results (unpublished)

Additional unpublished results are perceived change scores 12-months post-stroke. The scores below (Table 8) present the 13 additional questions of perceived change in the 12 domains of the SS-QOL scale, as well as perceived change in overall QOL. Only the two domains thinking (*p*=.011) and mood (*p*=.028), showed a statistically significant difference between the regions in favour of the Norwegian participants.

Table 8 Additional (unpublished) results



Reported change scores	Variables dichotomized	**Total population** N=369	
		N (%)	Total N (%)
Personality	[1] Changed	173 (47)	363 (98)
	Unchanged	190 (51)	
Energy	[2] Worse	261 (71)	367 (99)
	Unchanged	106 (28)	
Language	Worse	117 (31)	368 (99)
	Unchanged	251 (68)	
Mobility	Worse	169 (46)	367 (99)
	Unchanged	198 (53)	
Vision	Worse	115 (31)	363 (98)
	Unchanged	248 (67)	
Upper extremity function	Worse	121 (33)	362 (98)
	Unchanged	241 (65)	
Thinking	Worse	111 (30)	364 (98)
	Unchanged	253 (68)	
Mood	Worse	130 (35)	364 (98)
	Unchanged	234 (63)	
Work/Productivity	Worse	147 (40)	362 (98)
	Unchanged	215 (58)	
Self-Care	Worse	94 (26)	365 (99)
	Unchanged	271 (73)	
Do something for my family	Worse	119 (32)	363 (98)
	Unchanged	244 (66)	
Do something for my friends	Worse	132 (36)	360 (98)
	Unchanged	228 (62)	
Change in QOL	Worse	184 (50)	366 (99)
	Unchanged	182 (49)	

[1] Considerably changed, changed or a little changed than before

[2] Considerably worse, worse or a little worse than before

5 Discussion

In this section, general reflections and discussion about the main results, as well as a methodological discussion are provided. The chapter ends with implications for clinical practise, for further research, and health policy.

5.1 Discussion of the main results

In this project the overarching objective was to explore perceived quality of life (QOL) and functioning following stroke in two Scandinavian country-regions with different organisation of subacute rehabilitation services. The project employed both qualitative and quantitative data to gain both depth and contextual understanding, as well as broad and intended generalisable results through use of a multidimensional and stroke-specific health-related quality of life (SS-QOL) questionnaire. Perceived QOL and functioning are therefore conceptualised through different theories and frames of understanding, bringing forward an outlook of experienced QOL from diverse perspectives.

The three studies within this project brings value in a further understanding of QOL and functioning in the two country-regions. Paper I found that the Norwegian version of the SS-QOL scale is a reliable and valid instrument with good psychometric properties, and is suited for use in health research as well as in individual assessments of persons with stroke. Since paper I provided results regarding psychometric properties, it is discussed in the light of ‘the concept of health-related quality of life and measurement’. A main finding in paper II was the processual and situated changes stroke survivors experienced, and this was not easily relatable to results from the quantitative papers. Hence, this part also has its own discussion. Then complementary and divergent aspects of the main results from paper II and III are integrated, interpreted and discussed (Figure 4) through the aspects of; ‘rehabilitation services and impact of stroke’, ‘functioning in relation to quality of life’, and ‘fatigue’.

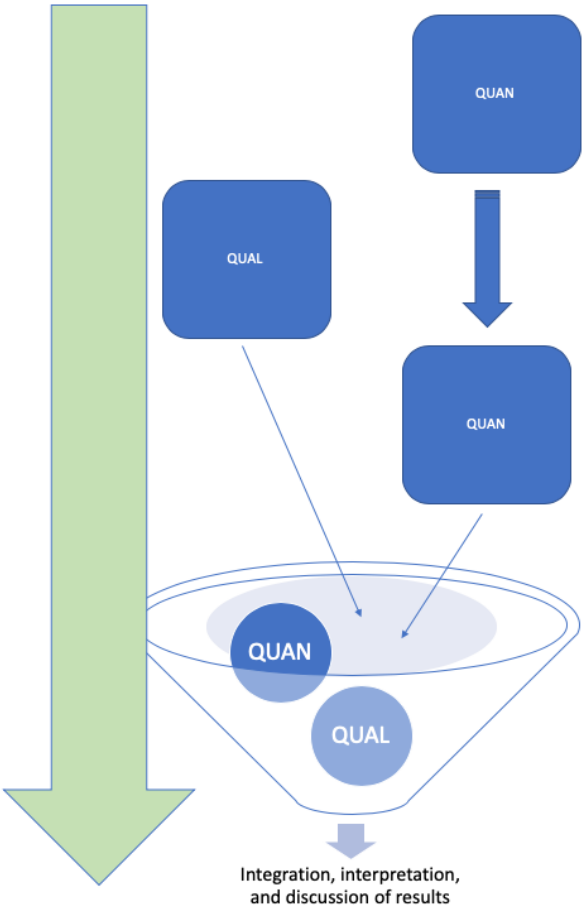


Figure 4 Integration with interpretation and discussion of results

5.1.1 The concept of health-related quality of life and measurement

There seems to be a rather common assumption that chronic conditions and functional impairments diminish a person's QOL (30), and stroke survivors report poorer self-rated health (233, 234) and HRQOL(235) compared to the general population. Instruments that have been developed to capture elements of QOL have various perspectives, that is, functions (107), health (236), well-being and/or satisfaction (70, 73). Some of the instruments that are primarily concerned with well-being or satisfaction are to a larger extent measuring adaptation or aspirations-achievements gaps and are not necessarily related to health or measuring HRQOL.

As in this study, many instruments include functioning as a central element and outcome in HRQOL. A reasoning behind functioning as an important HRQOL outcome relates to the circumstance that physiological disturbances or damage to cells, tissues, or organs systems may lead to symptoms that subsequently affect the functional status of the individual (177), hence influencing activities and participation as associated with the International Classification of Functioning, Disability and Health (ICF) (5, 107). In this study, paper I confirmed that measuring functions in the SS-QOL scale gave valid and reliable results. Further, the results from paper III demonstrated that functions were scored generally higher in the SS-QOL total scale in the regions of both North Norway and in Central Denmark compared to previous similar studies (237, 238).

The SS-QOL scale is mainly a measure of functioning, and incorporates areas of social functioning and roles, as well as cognitive and emotional aspects of functioning, and not just the aspect of physical functioning. Several of the domains, e.g. social function, family roles, and leisure activities, are related to the 'participation' perspective of involvement in life situations as described by the ICF (5). Comprehensive measures of HRQOL include items of physical, mental, and social domains of life (239), although the SS-QOL also includes the important domain of *energy* that not all stroke-specific measures include (57). Even if some of the generic measures do include the element of energy, they often lack more stroke-specific consequences like impact of vision, language, and cognition. The element of the energy-domain might be considered an advantage of the SS-QOL scale. Results from paper III showed that the energy domain had the lowest score in both country-regions and reflects how important this aspect is among measurements following stroke.

The process of developing HRQOL instruments has been criticised in regards to involving a sufficient number of disabled people in the design stage (239). However, the SS-QOL was derived through interviews with stroke survivors with their perspective of what affected their individual HRQOL after stroke (185). Evaluations of domains and items from both stroke survivors and health professionals with experience in the field of stroke were performed, and the reviews on item generation were repeated with different groups of stroke survivors until no substantial changes were observed (185). This patient-perspective through the design and development stage strengthens the content validity of this instrument.

How adequately the HRQOL measure and its assessment relate to the existing comprehensive frameworks of individual health and function, such as the ICF, should be explored further to allow outcome measures to be easily 'translated' into clinical meaningful frameworks (57). A few studies have linked and investigated the SS-QOL scale to the ICF classification of functioning and disability for content comparisons. One study (194) found that 41% of the SS-

QOL items related to *body functions*, 48% related to *activities and participation*, and 5.5% related to *environmental factors*, whereas 5.5% were not compatible with the ICF framework. The authors concluded that the ICF provided a useful framework for the conceptual understanding of the SS-QOL scale which covered meaningful components for stroke survivors (194). Another study (107), also found that the SS-QOL scales measurement of functioning relates well with the ICF, and particularly in relation to the participation aspect. Nevertheless, as argued by others (239), the feeling of health and QOL might be completely distinguished from disabilities in functioning: Some long-term stroke survivors with impaired functions might assess their health as good even if they are living with disabilities (234). This makes the question; 'HRQOL after stroke – What are we measuring?' (57) highly relevant. When measuring HRQOL, the documentation should reflect what the instrument is measuring (60), and additionally report 'HRQOL' or 'health' instead of 'QOL', which is basically is a wider-ranging concept as illustrated by the results from paper II.

5.1.2 Quality of life as process and fluctuating experience

Another feature of QOL is the processual and situated changes experienced by the stroke survivors. Hence, the concept involves a fluctuating aspect, temporal and adjusting, or moving back and forth depending on the individuals' situation. All humans have better or worse periods in life that are dependent on numerous and various aspects. For the stroke survivor, this might involve presence or absence of pain, degree of fatigue, acceptance, ability to adapt or adjust in different situations, emotions, and fluctuations in economic status (30, 56, 117). Hence, how life is perceived in the present moment might change with time, throughout recovery, and is dependent on a variety of factors or situations affecting the individual stroke survivor (51). These processual and fluctuating aspects are likely difficult to capture in a questionnaire.

The main finding from the qualitative data was the process of reconstructing the embodied self and the experience of QOL related to this process. The reconstructing process was influenced by bodily changes, social relationships, ability to do valued and meaningful things, as well as continuity and support from professionals.

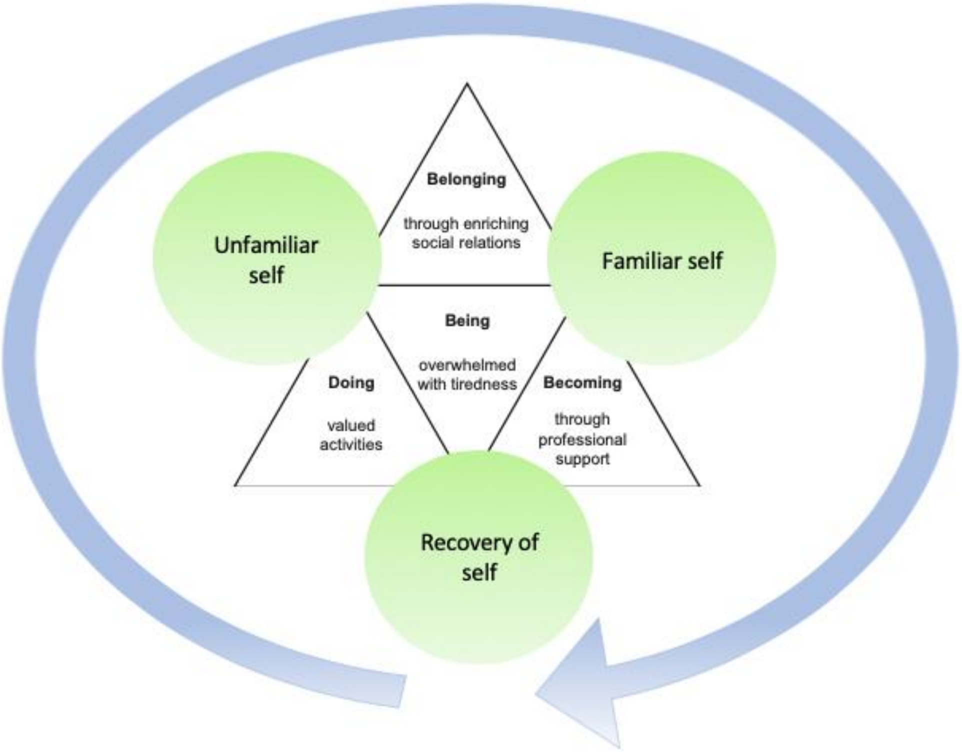


Figure 5 QOL as process

The three process-represented patterns in the narratives from the stroke survivors were identified and unfolded as: the unfamiliar self, the recovery of self, and the familiar self. These processes were dependent on both functional recovery and adjustments to the post-stroke life, as illustrated by the *being*, *doing*, *belonging,* and *becoming* aspects presented in paper II. Figure 5 is an integrated model of two models in paper II, illustrating the processual and interrelating aspects of reconstructing the embodied self. The perceived experience of reconstructing an embodied self was an intertwined and negotiating process for each individual, representing the processual and fluctuating aspect of QOL. This could be exemplified by a man that experienced a transformation from feeling very unfamiliar with his bodily changes, to gradually adjusting and accepting his post-stroke life as different, both in terms of what he could practically do, but also with regard to his social re-positioning in his familiar role within the family: *'I have lost the overview in terms of following up on practical things, and my wife is now the man in the house (...) I have accepted the situation for what it is, and I don't get annoyed or depressed by anything now'*. However, this man also explained that this acceptance felt ambivalent, and that some days, depending of different challenges in functions or emotional state, were less accepting than others, hence the fluctuating experience.

A meta-analysis (123) synthesized stroke survivors' views on the impact of stroke and their roles and self, although without the QOL-perspective. The difficulties in developing a (new) self and roles were highlighted, as well as the need for health professionals to assist stroke survivors to regain a sense of self and continuity (123). QOL and the self and identity aspects have been emphasised by others (26, 91), however, the findings in this study (paper II) illustrate the interrelations between body, self and QOL, as well as processes and fluctuations in the unfolding recovery process after stroke.

5.1.3 Rehabilitation services and impact of stroke

Organisation of rehabilitation services may impact on service quality and outcome for stroke survivors (13, 240). The qualitative results showed that the Danish participants considered their rehabilitation pathway throughout the first year following stroke more seamless and consistent than the Norwegian participants. In Denmark, rehabilitation services were regarded as a process influencing recovery and QOL, illustrated with statements as; *'it is the process in itself, the long-term plan that was made for me in the beginning, that has brought me back on my feet again'* (case 2), and *'because of it [the professional support] throughout this year (...), I am really at the best end of this situation now'* (case 4). These findings were consistent with other regional qualitative studies (142, 147, 148) conducted with the same group of participants. In addition, the available quantitative rehabilitation data indicated that the Danish participants to a higher degree received rehabilitation in the municipality, whereas the Norwegians received more in-patient rehabilitation.

In contrast to the descriptions from the Danish participants, the Norwegian participants described vulnerability in the smaller municipality-based health services, leading to absence and incoherent professional support, as also described in detail by others (142). These unmet needs were portrayed to impact recovery of functions and perceptions of QOL. Regional variations in availability of health professionals have also been reported by others (44). Longer term continuity in rehabilitation services have been deemed essential for persons with chronic needs in both countries policy documents (130, 146, 166), and the WHO establishes that any health systems' main objective should be promotion and protection of health, as well as maintaining the highest attainable level of population health (241). However, policy and intent might challenge structure and organisation within specific geographic areas such as the region in North Norway. The extent of stroke-related disability typically becomes more apparent after discharge from hospitals or in-patient rehabilitation (44), and for many stroke survivors long-term outcome remains poor (97, 134), and unmet needs are common (242). If the reception apparatus is small or low on resources, and patients are not regularly followed-up after discharge, these unmet needs might be difficult to both discover and address. In both country-regions, the acute stroke care and integrated in-patient rehabilitation are similar in terms of organisation, although the length-of-stay in stroke units are significantly different (figure 6). This length-of-stay variability might reflect capacity and resources in the subacute rehabilitation services, and whether the reception apparatus is capable of continuing the rehabilitation process with the individual stroke survivor. The findings in this study make an important contribution in terms of directing more attention to rural community-dwelling stroke survivors and their long-term needs to improve QOL for individuals. According to the Norwegian national guidelines for stroke treatment and rehabilitation (243), equality in stroke care is a principle no matter where you live. Further the recommendations urge health and care services in each municipality to follow up with rehabilitation adapted to the needs of the individual stroke survivor (243).

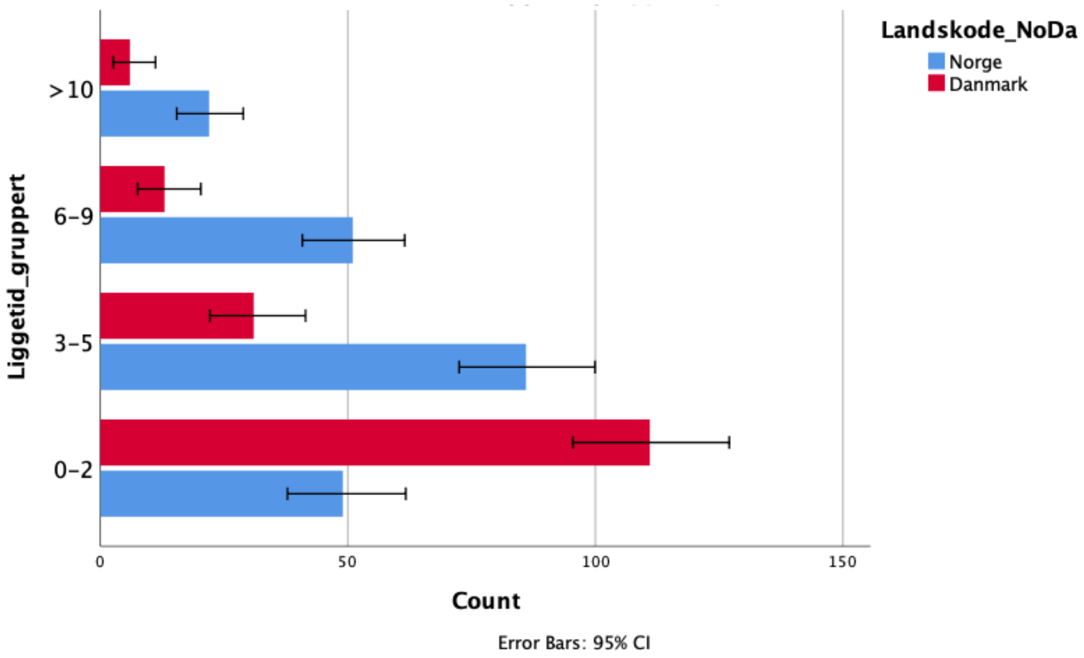


Figure 6 Length-of-stay regional differences

Considering the results from the interview study (paper II) and the related qualitative regional studies (142, 147, 148), our quantitative hypotheses of better functioning outcome in the population from Central Denmark was strengthened. However, the subsequent paper III analyses demonstrated that associations of 'country-region' on the SS-QOL scale were small, and unexpectedly, in the opposite expected direction. HRQOL scores were in favour of the North Norwegian participants when measuring both SS-QOL total, and the CSM and PH component of SS-QOL. Both countries scored better in physical functioning than in the domains related to cognition, social life and participation, and emotional and mental aspects. This is in contrast to studies that have reported more problems in physical domains than in cognitive and social domains (237, 244). In contrast, the dividing of component scores of the SS-QOL scale showed that aspects other than physical functioning remained more challenging one-year post-stroke in these two Scandinavian populations.

The combined results in relation to rehabilitation services, QOL and stroke impact in papers II and III have divergent aspects. In paper II, the value of continual long-term rehabilitation services for the experience of QOL and functioning are highlighted by the participants. This led to an impression of worse subacute municipal rehabilitation services in North Norway than in Central Denmark. Conversely, paper III showed that there was a small difference in SS-QOL scores between the regions, and that the Norwegians had overall better functioning. How can these divergent findings be understood? First, even if the quantitative data showed that the Danish participants received more municipal follow-up than the Norwegians, the Norwegians in contrast, received a higher degree of in-patient rehabilitation. This might be highly relevant to the initial recovery-phase were neuroplasticity with reorganisation of connectivity patterns (substitution) (245) in the brain are highly sensitive and more easily conformable (114, 245). In-patient rehabilitation offers intensive treatment and training, and this intensity is difficult to obtain in the municipalities. The extent of in-patient rehabilitation in the North-Norwegian region might have affected long-term functional outcome positively, an aspect that should be investigated further. Second, the qualitative inquiry had findings that related to *satisfaction with care*, and this aspect was not measured by the SS-QOL scale. Third, the qualitative sample was a younger group, and they all had attended in-patient rehabilitation. The qualitative results, interpreted within the framework of the entire study, and with differences in samples, might reflect both higher expectations to functioning with younger age (235, 246), as well as a sample with more complex disabilities than the included participants in paper III. In addition, the participants in paper II might have higher expectations to functional progress and municipal follow-up after experiencing intensive training and possibly more rapid progress during in-patient rehabilitation. As discussed in paper III, also cultural aspects might affect how populations rate and score in questionnaires.

Recently, functioning was recognised as the third indicator of health alongside with mortality and morbidity (102). Functioning is central in rehabilitation programs, with health and functions as primary outcomes, as well as evaluations of rehabilitation interventions and service delivery (102, 103). The quantitative findings of lower scores in both country-regions in the domains of energy, thinking, personality, mood, social roles, and family roles supplies valuable information of where more rehabilitation efforts are needed in the long-term perspective following stroke in the respective regions.

5.1.4 Functioning in relation to quality of life

Overall, the qualitative results demonstrated that functions were involved and interconnected to all aspects of life and important for QOL. Functioning had an impact on the aspects of *doing* valued activities, *belonging* in relationships, and *becoming* through evolving or adjustments moving forward in life. Further, functioning was important for the more fundamental *being* in the world, as well as part of the process of reconstructing the embodied self the first year following stroke, either through recovery of functions or through adjustments. Qualitative studies following stroke have shown that functions relate to QOL (26), although some studies have found aspects, such as appreciation of life, what you have and what you can do in your post-stroke life, social support, and support from health services to be more important (26, 91).

The additional presented results (Table 8) of the questions related to perceived pre- and post-stroke change within each functional domain of the SS-QOL and the overall QOL-question, revealed that even though functions were scored generally high in the SS-QOL 12 domain scale, perceived changes were marked in all of the pre- and post-stroke change questions. At a total population level, the perceived changes within the 13 pre- and post-stroke domains and overall QOL scores varied from 26% to 71%. Through the qualitative approach, the reasons for *why* functioning was important for QOL were described, and functioning, health and QOL can be understood as intertwining concepts in close relationship: ‘Optimizing functioning is the ultimate objective of rehabilitation, because being able to do what matters in our everyday life is what increases our well-being’ (103, p.539). In both country-regions, 50% of all participants reported a post-stroke decline in overall QOL (Table 8) compared to their pre-stroke perceived experience. This finding indicates that although functioning scores were relatively high in both countries, several participants are affected by their stroke one year later, even when the initial stroke severity was defined as mild and moderate. These results may relate to the ‘lived health’ as conceptualised by the ICF (5, 102), defined by what a person might be restricted in doing in his/her environment. The following example from the qualitative analyses can illustrate this further: *‘(...) It has a lot to do with quality of life – to work with what you really like doing’* (case 7). This man had returned to work, but he was environmentally restricted from working in his previous pre-stroke job. Although functioning, activity and participation were resumed at some level, the participant was not fully content with his work-situation, and was not able to continue his valued job, which influenced the experience of QOL.

5.1.5 Fatigue

The energy domain had the lowest scores in the SS-QOL scale in both countries. This domain has three items: 1) I felt tired most of the day 2) I had to stop and rest during the day, and 3) I was too tired to do what I wanted to do. In the qualitative study, tiredness was one of the main findings and described as a disturbing contributor to everyday life and to QOL. In paper II we discuss how fatigue interferes with *being*-in-the world and the lived experience. For the participants, tiredness interfered with life, and the aspect of fatigue might be one of ‘the hidden’ or more invisible impairments that are not obvious to the environment. Fatigue, or a feeling of weariness, is considered pathologic when it leads to decreased efficiency (247), and this was described by all participants in paper II, independently of how well they had recovered from their stroke. Although the mechanisms of post-stroke fatigue are not fully understood, several biological, psychological and behavioural factors might be associated with fatigue (248). A strong association between post-stroke fatigue and depressive symptoms, as well as a trend toward a connection to anxiety have been documented (249). Other studies have shown that limited exercise capacity, increased gait energy cost, and sleep-related disorders were associated with fatigue following stroke (247). Since the SS-QOL scale is one of the few HRQOL measures that takes fatigue into account, few studies were available for comparisons. However, one study (237) investigated Turkish stroke survivors with the SS-QOL scale, and found that the energy domain had an inverse relationship with age and a positive relationship with male gender. Younger stroke survivors might experience a decrease in efficiency more radically than older stroke survivors do, and younger individuals might also have higher expectations of efficiency than older people. This matter should be explored further in relation to stroke-specific HRQOL, as well as a possible gender differences related to fatigue.

The qualitative descriptions of fatigue had different character, and descriptions of both mental and physical tiredness were noted. A few participants portrayed a combination of the two. Most of the participants described mental tiredness with increasing concentration and thinking problems. According to the literature (247), mental fatigue appears during cognitive tasks. However, some of the narratives highlight a different aspect; *'If I do something physically hard, I get tired for a long time – but I do not get tired in my body, it is another tiredness within my head'* (case 10). Fatigue changed the participants' conception of their own capacity, and how they regarded their present self versus the previous pre-stroke self. This was described as restraining activity and participation, and negatively influenced the experience of QOL. In the quantitative pre- and post-stroke change question for the energy domain (Table 8), 71% (n=261) perceived their energy as changed for the worse post-stroke. This finding amongst stroke survivors with mild and moderate strokes as defined by categories of initial stroke severity measured by the Scandinavian Stroke Scale, should be further investigated. The results imply that fatigue is highly relevant for both QOL and HRQOL, and that there is a potential to follow-up and address fatigue among community-dwelling stroke survivors in both country-regions.

5.2 Methodological considerations

5.2.1 Study design for the thesis

Parallel mixed design

This overall design for the study has a number of strengths and advantages. First, it is an efficient design if mixed methods research (MMR) is chosen, as both types of data are collected roughly at the same time (152, 154). Further, each type of data can be analysed and kept independent of each other following specific analytic procedures or techniques associated with and appropriate for each of the study designs. The approach of this type of design is suitable for research within team collaboration, as in this study, with both quantitative and qualitative expertise. At the point of joint interpretation of the results, the combining and discussion of results may enhance a more comprehensive understanding of QOL, functioning and rehabilitation though both convergent and divergent interpretations (154, 158).

There are also several challenges in using the parallel mixed design, for example the effort and expertise required in the concurrent data collection (154). In this study intended procedures changed during the data collection phase due to an underestimation of the extent of this effort. The original plan was to additionally interview a small group of more average-aged stroke survivors. However, because of both a limited timeframe, and that I, together with experienced qualitative researchers, considered that the amount of data was sufficient to provide extensive in-depth analyses on the topic. Therefore, the change in procedures was more of a benefit than a disadvantage to the practicability in conducting this study. Further, in particular, I experienced challenges in addressing and continually distinguishing and comparing the concept of both QOL and HRQOL, as these concepts are understood, interpreted, and measured so differently. However, the two approaches of inquiry provided me with different aspects, which can be put together to generate a broader understanding of the study topic. For instance, the quantitative data provided broad results of the two cohorts, whereas the qualitative data captured aspects of the situated phenomenon and interchanging processes and fluctuation that can scarcely be measured by questionnaires.

When considering validity (250) for this design, ‘the unequal sample sizes may provide less of a picture on the qualitative side than the larger *N* on the quantitative side’ (158, p.223). Nevertheless, the quantitative and qualitative data are collected for different purposes, and qualitative interview studies usually ends their sampling procedure upon reaching a saturation point, and when the researcher(s) assume that additional interviews will not add anything new

(218). Undoubtedly, we cannot be sure that more interviews would provide additional and valuable information. An important validity-issue for this study's overall discussion is relative to the participants chosen for interviews, which resulted in a group of fairly young participants (range 35-66), and the circumstance for which they all had been admitted to in-patient rehabilitation after stroke unit discharge. Compared to the quantitative procedures with broad inclusion criteria, this might be considered a weakness of the study. The results might have been different if the inclusion criteria were more similar for both studies. However, with regards to our research questions and the comparison-perspective between the country-regions, the qualitative study required more strategically chosen participants with experience in rehabilitation to generate meaningful data.

Individual designs for the studies included in the thesis

Both papers I and III were conducted within a prospective observational study with outcome at one time-point. Prospective cohort studies have stronger design than cross-sectional studies (251). This design allows for capturing health-related outcomes and opinions, and regular time intervals might minimize recall bias as a systematic error (252). However, prospective studies may be time-consuming in following up a large number of individuals, and loss-to-follow-up can introduce bias (252). The first study (paper I) is a methodological validity study following procedures as described by the COSMIN guidelines, whereas the third study (paper III) investigated HRQOL in the included country-regions. Both studies collected baseline stroke registry data within high quality registries in both countries, and this can be considered a strength of the studies. In paper I, the follow-up was at 3 months, whereas in paper III we only included those who replied to our primary outcome measure at one-year after the stroke incidence within the larger study design.

The qualitative study (paper II) was conducted through an interpretative inductive approach seeking to understand the lived experience of the QOL phenomenon. The background philosophy was inspired by hermeneutic phenomenological interpretation, which inseparably connect human senses and subjectivity (253). The advantages of this approach are the structured data analysis (219), whereas the challenges are related to the general methodological encounters in qualitative approaches such as obtaining high rigor and robustness (253).

5.2.2 Reflexivity, credibility and transferability

Reflexivity reflects the awareness and accountability of the researcher's position (e.g. social, personal, political and professional beliefs) in the research process (254, 255). Reflexivity is viewed as the continual process and critical self-evaluation of positioning as well as acknowledgement and recognition that this position may affect the research process and outcome (255). For the qualitative study (paper II), my position will be outlined here in relation to the analytical process, as I did not directly take part in the interview process.

Ahead of this study, I had been invested in clinical work with stroke survivors for a decade. My work was in a hospital setting, and more specifically within a stroke unit. Making phone calls to the physiotherapy services in the municipalities to ensure smooth therapist-to-therapist transitions was part of my administrative work. However, in several instances it was difficult to find someone who could continue working with the stroke survivor within reasonable time, and in other instances it was difficult to find anyone at all. I have spent considerable time thinking about how life turned out for many of these individuals, and I have also spent considerable time talking to stroke survivors or their family members after home coming, especially when the transition back home did not go as smoothly as expected. My pre-understanding about the differences and variability in the municipal follow-up was therefore coloured by these experiences. Although, I obtained several good stories from recovery-phases and all the good things that happened 'out there', the stories of struggles often 'sits with me'. These pre-understandings were kept in mind throughout all the stages of analyses. At the same time, I had an open-minded approach to the data, in which both positive and negative experiences among the participants were sought. Since parts of the results-section particularly addressed municipal follow-up as a divergence between the country-regions, critical self-reflection and team collaboration to verify the findings became especially important.

In qualitative research, human emotions and perspectives from both participants and researchers are considered both essential and inevitable for generating knowledge (253, 255). For credibility of results, issues of rigor and trustworthiness are also important to discuss (253, 255). Transparency and systematicity for the research-process are important principles for fulfilment of quality criteria in qualitative research (253). In this study (paper II), two factors were particularly important for transparency and systematicity in the research process: 1) the collaborative team process where all had close knowledge of the data material, and 2) the use of the systematic text condensation (STC) analytic tool. For myself as the primary developer in analyses, the repeated readings and discussions among the research group, the reflexive journal, as well as the matrix generated from the STC, made the material and analyses systematic and transparent to others. Because I did not take part in performing the interviews myself, my interpretation of text could possibly conflict with the overall impressions of meanings derived from the interviews. Hence, my interpretations were validated through these procedures. The ‘outside-perspective’ might also have some advantages from an analytical standpoint, with for example an emotional distance from the participants.

Transferability reflects how the findings in a study can be significant beyond a particular and an individual context (256). Paper II present results with theoretical abstraction, as well as abstraction of QOL as essential features that are transferable to other sociocultural settings, for example, reconstruction-of-self interactive processes that might be essential to several stroke survivors across country boundaries. However, the contextual nature of this research also implies that other results, such as evidence of variability in health professionals’ follow-up, might be very contextually bound, and might not relate to other individuals with stroke or to other regions in Norway or Denmark. Hence, careful thought must be given to the potential transferability of the results to other contextual settings (257)

5.2.3 Representativeness and generalisability

In the validation study (paper I) the response rate was 78% (125 of 161 eligible participants), and in the prospective follow-up study (paper III), the response rate was 59% (369 of 627 eligible participants). Both samples represent responses mainly from individuals with mild and moderate strokes, as in several other comparable studies (185, 190, 244). A non-response bias may occur if responders differ substantially from non-responders (258), which may be the case here as those with more severe stroke were less likely to not respond. For that reason, both studies were specific with regard to interpretation of results relative to stroke survivors with mild and moderate stroke, and not severe stroke. The conclusions withdrew should thus generalize well to these subpopulations, but extends less well to more severe populations. Additionally, the non-responders were of older age in the validation study (paper I). The response rate (paper III) in North Norway was slightly higher than in Central Denmark (60% vs 57%, respectively); however, this was a rather trivial difference worthy of less concern.

In paper III, a selection bias could limit the generalisability of the results as the study samples differed between the country-regions. The participants from Central Denmark were younger (*p*<.05) than the participants from North Norway and had less initial stroke severity (*p*<.01). Different stroke unit admission practices could be one possible explanation for this difference, or recruitment procedures for the study. However, we have tried our best to correct for the differences by including these covariates in regression analyses.

Self-reported data are valuable for providing a wide range of responses, and for obtaining the individual's own perspectives, views, and opinions (177, 259). A strength of our study was a high completeness rate in these data both in papers I and III. However, self-reporting bias, such as scores being unduly affected by social desirability bias or recall bias (259), may occur. Social desirability is of less concern if the context of the study does not invite participants to over or understand their responses. That may be the case if the individual believe overstating problems may arouse access to desired treatment options they otherwise perceive them excluded from. We have no indication of that possibly being the case. Another strategy for reducing social desirability bias is to properly validate the instrument before implementing it for data collection (259), as we did in paper I. Recall bias should be of less concern as the SS-QOL scale invite the individuals to report their current understanding and experience of their life situation. However, the interview questions regarding rehabilitation comprised questions concerning the previous 3 months, and for these questions recall bias might be a concern. The questionnaire length may represent an issue in this study with regards to 'no-saying' or 'yes-saying', which indicates response fatigue resulting in uniform and inaccurate answers (260). Since response fatigue introduces random error rather than systematic errors in scores(259), it should cause a reduced reliability (i.e., lower Cronbach's alpha) if overly present. As the measurement reliability was considered adequate, we consider response fatigue as a minor problem in this study.

The prospective observational design and overall acceptable response rate, together with results converging relatively well with existing studies, indicate that the results from this study (papers I and III) generalise well to at least comparable populations (mild and moderate stroke). In paper I we achieved a high response rate and a sample size comparable to related studies, and in paper III we achieved a larger sample size in measuring stroke-specific HRQOL than for most other studies. However, some caution must be made relative to the selection bias in paper III. High quality data from stroke registries combined with questionnaires with a low degree of missing data minimise the risk of information bias (259, 260), and this also represent a strength of the study.

5.2.4 Study implications

Clinical implications

- The Norwegian version of the SS-QOL scale is suited for use in individual assessments of persons with stroke. The SS-QOL scale mainly measures functions and can be viewed in relation to clinical meaningful frameworks, such as the ICF.
- The stroke-specific health related quality of life (SS-QOL) assessment tool captures multidimensional effects of a stroke from the perspective of the patient, which is clinically important information for rehabilitation services. The two components of the scale, cognitive-social-mental (CSM) and physical health (PH), may indicate specific functional problems that each individual with stroke perceive as problematic.
- For individuals with mild to moderate stroke, longer-term functional improvements may be optimised if the rehabilitation services particularly address cognitive, emotional, and social functioning.
- In rural areas having a lack of integrated multidisciplinary community-based rehabilitation services post-stroke, available specialised in-patient rehabilitation is an important alternative.
- The process of reconstructing the embodied self after stroke can be strengthened by health services by optimizing functioning or support adjustments to everyday life so that the individual is moving forward in this process.
- Health professionals can enhance QOL through *being, doing, belonging and becoming* perspectives, from the position of what each individual finds meaningful and valuable in their own life. This might involve establishing groups of peers, resumptions of valued

activities, or facilitating return to work, developing structured plans, or facilitate coping strategies, e.g., for balancing activity and restitution, in everyday life.

- Fatigue is a highly relevant long-term functional problem to address and support among community-dwelling stroke survivors, even in individuals with mild and moderate stroke.

Implications for future research

- The Norwegian version of the SS-QOL scale is appropriate for use in health research. However, the psychometric properties of the vision domain were not satisfactory within the test-retest correlation, and we suggest rephrasing at least one of the three items and then re-validating the domain.

- The cognitive-social-mental (CSM) component and the physical health (PH) component, indicate specific functional difficulties, which may vary across and within countries and regions, and might be useful in research studies examining the characteristics of different populations that have suffered a stroke.

- How to organize and improve subacute rehabilitation services should be further investigated. For long-term functioning, specialised in-patient rehabilitation services could be as important as better organisation of municipality-based rehabilitation services, particularly in rural areas.

- Fatigue after stroke should be further explored. As a phenomenon fatigue should be explored in relation to expectation of capacity and efficiency.

- Satisfaction with care and rehabilitation might differ between regions with dissimilar subacute rehabilitation services, and this should be explored further.

Implications for health policy

Long-term follow-up of stroke survivors in the region of North Norway has the potential to improve QOL and functioning following a stroke. In this study, the region in Denmark to a larger extent provided municipality-based follow-up of patients. Further, the descriptions of the value that this type of continuity had on QOL was apparent, and very different from the descriptions of discontinuity or lack of follow-up that several participants from North Norway described. In Denmark, the municipalities are obliged to follow-up individuals given a personalized rehabilitation plan, and this might facilitate a more smooth and consistent rehabilitation-pathway for each individual. A more obligatory requirement to course of action towards individuals with stroke in the municipalities in North Norway, could facilitate more seamless rehabilitation-pathways and a higher level of QOL and functioning following stroke. This should be coordinated with continued availability of specialized in-patient rehabilitation in the early subacute phases.

6 Conclusions

To my knowledge, this is the first study investigating stroke-specific HRQOL and quality of life across countries with unalike organization of subacute rehabilitation services with a mixed methods approach.

This study found that the Norwegian version of the multidimensional Stroke-Specific Quality of Life scale is a reliable and valid instrument with good psychometric properties, as well as suited for use both in individual assessments and in health research. The physical health (PH) component and the cognitive-social-mental (CSM) component may indicate specific treatment or rehabilitation needs at an individual level or in different populations. Across the country-regions depression, anxiety, pre-stroke dependency, higher initial stroke severity, and older age were substantially associated to worsen SS-QOL scores.

The overall quality of life question of perceived change pre- and post-stroke illustrated that half of the participants in both regions reported a negative change in QOL despite fairly good average HRQOL functional scores. Although functioning is an important aspect of quality of life, quality of life is also dynamic, relational and situational. Stroke survivors might have different expectations and aspirations in regards to functioning in a post-stroke life. As demonstrated by the qualitative inquiry, the process of reconstructing the embodied self through progress or adjustments was an essential aspect of recovery and quality of life. Stroke represented a discontinuity of life, and rebuilding, accepting or adjusting was part of a processual and fluctuating QOL experience.

The levels of functioning measured by the SS-QOL scale, showed that the participants from the Danish region reported more functional problems in the SS-QOL scale and in the two components scales after adjustment for predefined covariates. This finding did not confirm our expectation of better self-reported HRQOL one-year post-stroke in the Danish region with more structured subacute multidisciplinary community-based rehabilitation services. The investigated geographic region in Denmark has systematically developed competence in cognitive rehabilitation, and participants in this region received more municipality-based rehabilitation after stroke unit or in-patient rehabilitation discharge than the Norwegian participants. Speculatively, these conditions might affect stroke survivors’ insight into their own functional dilemmas regarding cognition, and result in more reported problems. However, the North Norwegian participants received in-patient rehabilitation to a higher degree, which may have impacted one-year functioning positively. The difference could also be caused by selection bias or cultural aspects, and should be further investigated.

Nevertheless, participants from both regions experienced significantly more problems within the CSM component than in the PH component, one-year post-stroke. Although the differences between the regions were significant, the magnitude was minor (small Cohens' *d*). This finding indicates that longer-term functional improvements following mild and moderate stroke in both countries could benefit from rehabilitation services particularly addressing cognitive, emotional, and social functioning. The two country-regions differed in descriptions of continuity and support in the professional follow-up during the recovery process, indicating benefits from the well-organised community-based rehabilitation in Central Denmark.

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PAPER I

Synne Garder Pedersen, Guri Anita Heiberg, Jørgen Feldbæk Nielsen, Oddgeir Friborg, Henriette Holm Stabel, Audny Anke, Cathrine Arntzen. ***Validity, reliability and Norwegian adaptation of the Stroke-Specific Quality of-Life scale***. SAGE Open Medicine 2018; 6: 1-10

Original Article

SAGE Open Medicine

SAGE Open Medicine
Volume 6: 1–10
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2050312117752031
journals.sagepub.com/home/smo

Validity, reliability and Norwegian adaptation of the Stroke-Specific Quality of Life (SS-QOL) scale

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Abstract

Background: There is a paucity of stroke-specific instruments to assess health-related quality of life in the Norwegian language. The objective was to examine the validity and reliability of a Norwegian version of the 12-domain Stroke-Specific Quality of Life scale.

Methods: A total of 125 stroke survivors were prospectively recruited. Questionnaires were administered at 3 months; 36 test–retests were performed at 12 months post stroke. The translation was conducted according to guidelines. The internal consistency was assessed with Cronbach's alpha; convergent validity, with item-to-subscale correlations; and test–retest, with Spearman's correlations. Scaling validity was explored by calculating both floor and ceiling effects. A priori hypotheses regarding the associations between the Stroke-Specific Quality of Life domain scores and scores of established measures were tested. Standard error of measurement was assessed.

Results: The Norwegian version revealed no major changes in back translations. The internal consistency values of the domains were Cronbach's alpha = 0.79–0.93. Rates of missing items were small, and the item-to-subscale correlation coefficients supported convergent validity (0.48–0.87). The observed floor effects were generally small, whereas the ceiling effects had moderate or high values (16%–63%). Test–retest reliability indicated stability in most domains, with Spearman's rho = 0.67–0.94 (all $p < 0.001$), whereas the rho was 0.35 ($p < 0.05$) for the 'Vision' domain. Hypothesis testing supported the construct validity of the scale. Standard error of measurement values for each domain were generated to indicate the required magnitudes of detectable change.

Conclusions: The Norwegian version of the Stroke-Specific Quality of Life scale is a reliable and valid instrument with good psychometric properties. It is suited for use in health research as well as in individual assessments of persons with stroke.

Keywords

Stroke-Specific Quality of Life scale, stroke, validity, reliability

Date received: 28 June 2017; accepted: 12 December 2017

Introduction

Stroke has been ranked among the most common causes of disability worldwide[1,2] and is associated with a decrease in health-related quality of life (HRQOL).[3–5] Traditionally, outcome assessments in stroke rehabilitation have focused on improvement in symptoms and restoration of function, whereas patient-centred assessments, such as subjective well-being and HRQOL, are a more recent initiative.[6] Patient-reported outcomes (PRO) enhance our understanding of treatment outcomes by indicating the impact of disease symptoms from the individual persons' perspective.[7] Of these measures, HRQOL has been recognized as increasingly important after stroke

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because it improves our understanding of the impact of symptoms on persons' lives and enables us to evaluate how treatment affects persons' functioning and well-being.[7]

Numerous generic and disease-specific scales that measure HRQOL after stroke are available. Generic instruments are frequently used to compare HRQOL outcomes across populations and diseases, while disease-specific instruments assess more nuanced states or concerns of specific diagnostic groups.[8] A limitation of generic instruments is the lack of specificity regarding the quality of life-related consequences of a particular condition, such as stroke.[9] Furthermore, they do not detect clinically relevant changes in HRQOL for a specific condition.[10] The Stroke-Specific Quality of Life (SS-QOL) scale is a HRQOL measure that is specific and clinically relevant for assessing persons with stroke. The SS-QOL scale is a multidimensional PRO measure that assesses specific aspects of functioning and HRQOL issues relevant to ischaemic stroke survivors. As part of a current multicentre stroke study in Norway and Denmark, we decided to adapt the SS-QOL. However, although it has been validated and applied in Denmark, it has not been validated for use in Norwegian stroke survivors.

The original SS-QOL questionnaire measures 12 domains with 49 items. The domains and items were derived from interviews with stroke survivors in the United States.[11] The SS-QOL scale has also been validated for persons with aneurysmal subarachnoid haemorrhage.[12,13] The validity of the SS-QOL scale has been examined in persons after stroke in various countries, for example, in Denmark with an ischaemic stroke population,[14] Nigeria (Yoruba language),[15] Mexico,[16] and Germany, where a short and long version for survivors of haemorrhagic or ischaemic stroke has been validated.[17] A version with 8 instead of 12 factors was proposed that replicated the eight factors well. Hsueh et al.[18] compared the construct validity of the 8- and 12-domain versions but favoured the latter, as it covered additional domains, thereby enhancing participants' perspectives on HRQOL.

The objective of this study was to (1) translate and cross-culturally adapt the 12-domain SS-QOL scale, version 2.0, into Norwegian for persons with ischaemic and haemorrhagic stroke; (2) examine the scale reliability (internal consistency) and test–retest stability, and (3) assess aspects of the construct validity of the Norwegian scale.

Methods

Participants

This validation study was part of a multicentre cohort study, including persons 18 years or older with acute ischaemic (I63) or haemorrhagic stroke (I64). Persons with stroke admitted to one of the three stroke units at the University Hospital of North Norway who were living in the region were invited to participate. Stroke survivors excluded from the Norwegian National Stroke Register were also excluded from this study, for example, those with stroke related to brain malignancy, subarachnoid haemorrhage and/or traumatic brain injury (TBI).

From March 2014 through December 2014, this study prospectively included 125 participants who completed or nearly completed the SS-QOL questionnaire at 3 months after stroke. These participants accounted for 58% of the 214 eligible stroke survivors during the defined recruiting period (Figure 1). The response rate was 78% (125 of 161 eligible), and among these, 41 participants (33%) received support filling out the forms. The size of the recruited sample was based on the sample size used in comparable published studies examining related research hypotheses.[14]

Table 1 shows the sociodemographic and stroke characteristics of the 125 participants. The median age was 72 years (range 25–96 years). Over 90% lived in their homes at 3 months, and 73% did not need any assistance.

Data collection procedures

Stroke survivors were informed about the study by nurses in the stroke units or by health professionals responsible for updating the information in the Norwegian National Stroke Register. Each hospital had one to three local health professionals who collected all the data and asked for participants' written consent, which was obtained prior to commencing the study. A questionnaire package was mailed to the participants' home address 3 months post stroke. Marital status, education and work status were collected from the questionnaires. Information on age, gender, living situation, stroke characteristics and modified Rankin Scale (mRS) was obtained from stroke registry data. The mRS is a scale that measures the degree of disability or dependence in activities of daily living (ADL).[19] The scale ranges from 0 to 6 ('perfect health to death') and is widely used internationally throughout hospital services.

A sub-sample of 40 persons provided the consent to participate in a test–retest study at 12 months post-stroke onset, as stability in disease functioning and HRQOL scores may be presumed.[20,21] Among the 40 recipients of the SS-QOL at 12 months, 36 responded within the desired timeframe. We re-administered the tool within 7 days from the date of the first administration. The COSMIN guidelines (consensus-based standards for the selection of health measurement instruments) were used as a checklist in the validation process.[22]

Predefined hypotheses

As suggested by Mokkink et al.,[22,23] we predefined hypotheses for the directions and magnitude of construct relationships (i.e. correlation patterns and sizes) based on the available literature or, alternatively, a priori consensus discussions between two of the authors (S.G.P and A.A.). Construct validity was considered supported if ≥75% of the results were in correspondence with these hypotheses.[24] Convergent

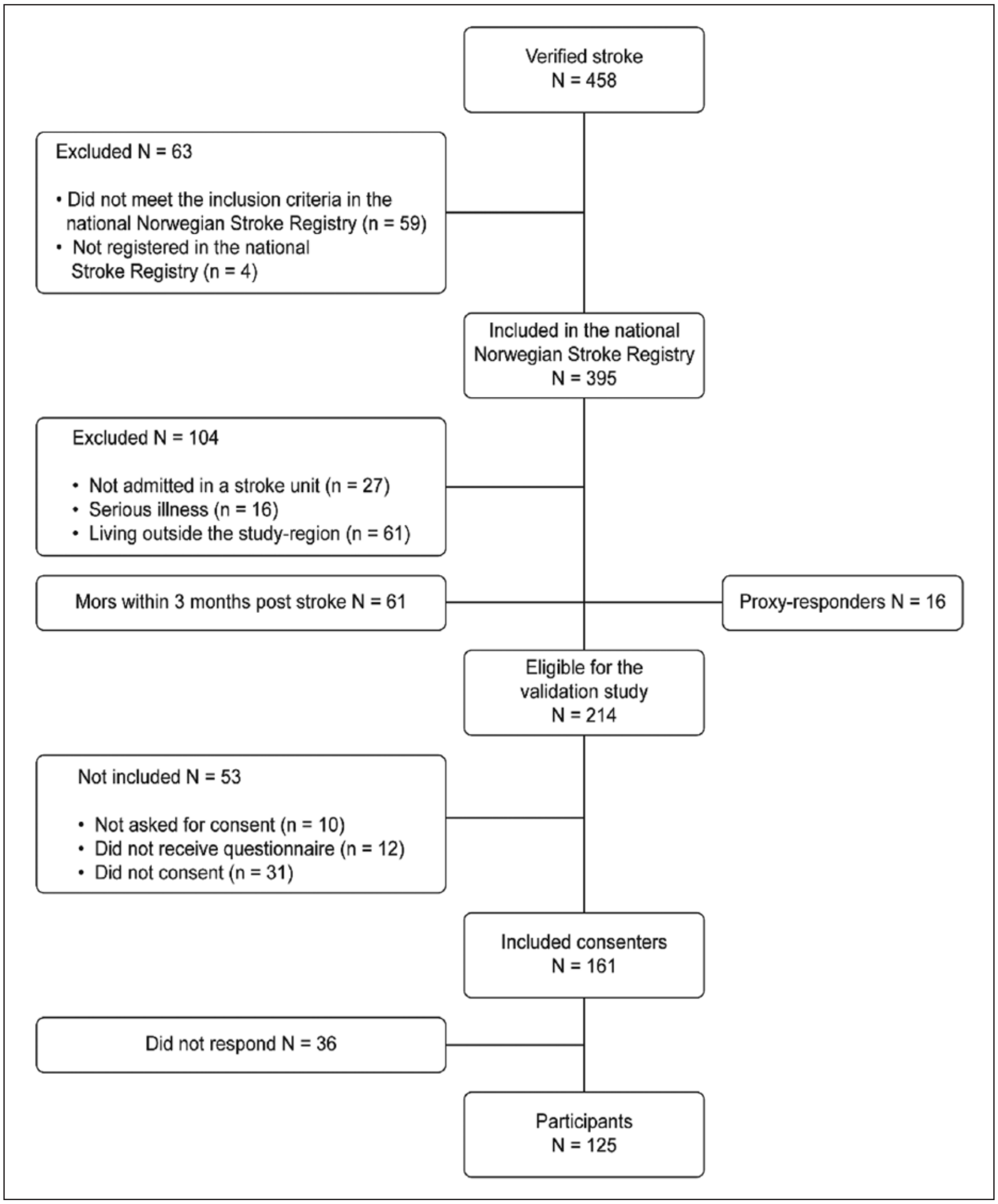

Figure 1. Flowchart of persons with acute ischaemic or haemorrhagic stroke registred in the county of Troms in Norway during the recruiting period.

validity was established by comparing the linear association of the individual domain score with the score of an established outcome measure for that specific domain. None of the established measures covered the Vision and Language domains, and these domains were thus tested with single items from the Norwegian National Stroke Register. In the first three columns of Table 2, the domains and corresponding outcome measures (all previously validated in Norwegian), as well as the predefined hypotheses regarding construct relationships, are presented. We expected significant positive correlations between related HRQOL constructs. We expected negative correlations between the SS-QOL domain scores (i.e. Energy, Mood and Personality and total score) and measures of global psychological distress and depression (Hospital Anxiety and Depression Scale: total and depression score). No significant correlation was expected between the SS-QOL score and participants' gender.

Measurements

Stroke-Specific Quality of Life (SS-QOL) scale, version 2.0, by Williams et al.[11] consists of 49 items covering 12 domains: Mobility, Energy, Upper Extremity Function, Work and Productivity, Mood, Self-Care, Social Roles, Family Roles, Vision, Language, Thinking and Personality. Each domain is measured by three to six items using a 5-point (1–5) Likert

Table 1. Sociodemographic and stroke characteristics.

	Responders (N = 125)
Age at the time of injury, mean (SD)	70.5 (13.1)
Gender, n (%)	
Female	48 (38)
Male	77 (62)
Stroke subtype, n (%)	
Ischaemic	113 (90)
Haemorrhagic	12 (10)
Marital status, n (%)	
Married/cohabitant	80 (64)
Widowed/single	45 (36)
Education, n (%)	
≤10 years	60 (48)
>10	62 (50)
Unknown	3 (2)
Living conditions at 3 months, n (%)	
Home, without assistance	92 (73)
Home, with assistance	23 (19)
Institution/residence for elderly	10 (8)
Work status at 3 months, n (%)	
Student/unemployed/working fulltime or part-time	23 (18)
Retired/sick-leave	102 (82)
Modified Rankin Scale at 3 months, n (%)	
0–1 no symptoms or no significant disability	84 (67)
2–3 slight or moderate disability	33 (26)
4–5 severe disability	8 (7)

SD: standard deviation.

scale (higher scores indicate better function). An average non-weighted raw score for each domain can be generated. The overall SS-QOL summary score is most often used as the primary outcome, although the separate domain scores are helpful for identifying specific areas that are affected by stroke or that improve the most or least over time.[11] The validity of the SS-QOL has been examined when administered by telephone,[25,26] self-report and mail[14] and with proxy responders.[17,27]

The Quality of Life After Brain Injury, Overall Scale (QOLIBRI-OS) is a brief HRQOL index originally constructed as a self-report scale for persons with TBI.[28] The QOLIBRI-OS measures six functional areas using single-item questions assessing the following: (1) physical condition, (2) cognition, (3) emotions, (4) function in daily life, (5) personal and social life and (6) current situation and future prospects. Each item is scored from 1 ('not at all') to 5 ('very'), and the sum score is arithmetically converted to a percentage score from 0 to 100 (worst–best).[28] The QOLIBRI-OS has demonstrated good validity and reliability in persons with TBI[29] and subarachnoid haemorrhage[30] and was recently validated for use in persons with stroke.

The EuroQol Quality of Life Scale-5D (EQ-5D) is a generic HRQOL measure that evaluates five dimensions: mobility, self-care, ADL, pain, and anxiety/depression. Self-ratings were categorized into three groups in relation to possible levels of problems (1 = no, 2 = mild/moderate, and 3 = severe).[31] It is possible to assign health-state utility indices based on different value sets, although according to the literature,[32,33] construct validation should be performed on descriptions of the five dimensions and not the preference-based index that can be derived from the measure. In this study, we used individual dimensions to test the construct validity. The total score was used to test the convergent validity of the total SS-QOL scale. The EQ-5D has been evaluated extensively in different cultures and languages, and it was designed to be self-administered and quick enough to complement other quality of life measures.[31]

EuroQol Visual Analogue Scale (EQ VAS) is the second part of the EQ-5D questionnaire. The participants rate their state of health by drawing a line from a box marked 'Your health state today' to a point on the VAS scale, which ranges from 0 to 100 (worst to best imaginable health).[31]

Hospital Anxiety and Depression Scale (HADS) consists of 14 items that assess non-vegetative symptoms of depression (7 items) and anxiety (7 items). It can be used to reliably and validly detect these two mental health states.[34] The HADS has been used as a screening tool in several languages and is particularly suited for hospital populations,[35] including persons with stroke.[36] It uses a response scale of 0–3 (higher is

Table 2. Construct validity of the SS-QOL scale domains: Results of hypotheses testing in 125 participants 3 months post stroke.

SS-QOL domain	Measure	Correlation hypothesis	Spearman's ρ
Mobility	N-NSR item 'Mobility'	Low to moderate	0.47
	EQ-5D domain 'Gait'	Moderate to high	0.63
Energy	HADs total score	Moderate to high (negative)	−0.65
	EQ-5D: EQ VAS scale	Moderate to high	0.48
Upper extremity function	N-NSR self-care 'Getting dressed'	Low to moderate	0.47
	EQ-5D domain 'Usual activities'	Moderate	0.62
Work/productivity	EQ-5D domain 'Usual activities'	Moderate to high	0.73
Mood	HADs depression	Moderate (negative)	−0.65
Self-care	QOLIBRI-OS item 'Daily activities'	Moderate to high	0.54
	EQ-5D domain 'Personal hygiene'	Moderate to high	0.68
Social roles	QOLIBRI-OS item 'Personal and social life'	Moderate to high	0.56
	QOLIBRI-OS total score	Moderate	0.62
Family roles	QOLIBRI-OS item 'Personal and social life'	Moderate to high	0.58
	QOLIBRI-OS total score	Moderate	0.64
Vision	N-NSR item 'problems with vision not present prior to stroke'	Moderate	0.25
Language	N-NSR item 'Problems speaking not present prior to stroke'	Moderate	0.42
Thinking	QOLIBRI-OS item 'Concentrate/remember/thinking'	High	0.65
	QOLIBRI-OS total score	Moderate	0.64
Personality	QOLIBRI-OS item 'Feelings/emotional state'	Moderate to high	0.48
	HADs Depression	Low to moderate (negative)	−0.52
SS-QOL total	QOLIBRI-OS total score	Moderate to high	0.71
	EQ-5D total score	Moderate	0.73
	HADs total	Moderate to high (negative)	−0.69
	Gender	No correlation	−0.17

N-NSR: Norwegian–National Stroke Register at 3 months. Single-item questions (n = 112–114). EQ-5D: The EuroQol Quality of Life Scale-5D; HADs: Hospital Anxiety and Depression Scale; QOLIBRI-OS: The Quality of Life After Brain Injury, Overall Scale; SS-QOL: Stroke-Specific Quality of Life scale (n = 125)
Correlation coefficients: ±0.1 small; ±0.3 medium; ±0.5 large.

worse). Subscale sum scores range from 0 to 21,[34] and a cut-off score ≥8 has been used to indicate a potential diagnosis of depression[37] in Norwegian samples. The total HADS score (range 0–42) can additionally be considered a global measure of psychological and emotional distress.[38]

Stroke registry data. To test convergent validity, responses to the ADL questions 'Mobility' and 'Getting dressed' from the Norwegian National Stroke Register were used, as well as 'Problems with vision' and 'Problems speaking' (not present prior to stroke).

Translation and cross-cultural adaptation

The translation process followed standard guidelines, which included forward–backward translation, expert validation and field testing.[39] Three bilingual translators conducted independent forward translations from English to Norwegian. A multidisciplinary, bilingual committee of four health professionals, all with a neurological background and special competence in stroke, prepared a reconciled Norwegian language version from the translations. The committee also reviewed the introductory statements and the instructions for the questionnaire. Three independent, bilingual health professionals performed the back translations from the Norwegian to the English version. Disagreements were resolved through discussion, and the discrepancies resulted in small changes to the Norwegian version, explained below.

In the English version, the response categories for the domains Mobility, Upper Extremity Function, Self-Care, Vision, Language and Work/Productivity were 'Couldn't do it at all', 'A lot of trouble', 'Some trouble', 'A little trouble' and 'No trouble at all'. In Norwegian, trouble and difficulty have the same meaning, but difficulty is more commonly used. This modification was made based on the different back translations generated. As in the Danish version,[14] the response category for 'personality' in the additional psychometric section of the questionnaire was altered to obtain a more appropriate response in Norwegian. Explanatory examples within the items were excluded in the Norwegian version. To ensure that the translation was fully comprehensible, four participants admitted to a stroke unit were asked to complete the questionnaire and provide feedback if they found any item, response category or instruction unclear or misleading.

Statistical analyses

All analyses were conducted in SPSS 23. The distributional properties of the subscales were examined visually and parametrically (e.g. kurtosis and skewness). The descriptive data were presented as the means, standard deviations (SDs) and ranges or as proportions. Chi-square (or Fisher's exact) tests were used to compare categorical data, whereas independent-sample t-tests were used to compare the mean differences between two groups. Non-normally distributed data were examined with non-parametric statistical analyses (e.g. Mann–Whitney test). Occasionally missing items were replaced with the mean of the subscale if less than three items were missing. The internal consistency of the SS-QOL total and domain scores were examined by calculating Cronbach's alpha values (higher than 0.7 are preferable).[40]

Floor and ceiling effects were calculated as the percentage of participants with the minimum or maximum score in each domain. Floor and ceiling frequencies higher than 15% were considered substantial.[24] Item-total correlations within the range of 0.4–0.9 were considered acceptable.[41] Test–retest stability was examined by two means: (1) Spearman's ρ, to quantify the magnitude of the relationship between the scores on the first and second administration, which should preferably surpass 0.7,[24,40] and (2) intra-class correlation coefficients (ICCs), to assess stability in the use of the response scale by comparing the consistency with absolute agreement estimates. The ICC should also surpass 0.7.[24] A distribution-based method was used to calculate the standard error of measurement (SEM). The formula was based on Cronbach's alpha and the SD.[42]

Data quality

All primary missing data were recorded and summarized for each item in the SS-QOL questionnaire. Missing data were collected from participants by telephone when possible, and when not, the mean of the domain score was used as a replacement when only one or two items were missing from the total scale. SS-QOL questionnaires with more than two missing were not included in the study.

Ethics

This study was conducted according to the Helsinki Declaration regarding informed consent and confidentiality. The Regional Norwegian Ethical Committee Health Region North approved the study (2013/1461).

Results

Translation

The forward- and back-translation process confirmed a satisfactory match in semantic meaning between the original and the back-translated SS-QOL items. The few exceptions were resolved through consensus discussion, which resulted in removing explanatory examples and revising the layout, for example.

Missing data

The degree of missing data in the SS-QOL was very low (1.4%), and these data were replaced by consulting the participants or using the domain mean (Table 3). The most frequently missing item was 'I had sex less often than I would like', which was in the Social roles domain.

Ceiling effects

The SS-QOL total score had an acceptably low ceiling effect (8.8%), whereas all the domain scores had ceiling effects surpassing the 15% limit (Table 3). The domains Self-Care, Vision and Language had considerable ceiling effects (above 50%). Conversely, floor effects were predominantly absent.

Reliability

The domains of the SS-QOL scale showed acceptable and good internal consistency, with Cronbach's alpha coefficients ranging from 0.79 to 0.93. The alpha value for the SS-QOL total score was 0.97. The item-total correlations ranged between 0.44 and 0.83 for all 49 items.

In all, 36 participants returned the retest, enabling an examination of the measurement stability. The test–retest stability was generally good, as Spearman's correlations were all high (Table 3), except for in three domains with coefficients below 0.7 (Thinking ($\rho = 0.65$), Energy ($\rho = 0.66$) and Vision ($\rho = 0.35$)). The ICC values were excellent for all domains. The differences between the consistency and the absolute agreement-based ICC estimates were minor, thus indicating that participants interpreted the response scale similarly at both measurement occasions.

SEM

The SEMs are presented in Table 4 and indicate the smallest degree of change in the total or domain score that reflects a true change in the construct, that is, not confounded by measurement error. A change score of at least

Table 3. Reliability of the Norwegian version of the SS-QOL scale – data quality, internal consistency, floor and ceiling effects and test–retest reliability.

SS-QOL domain (N = 125)	Numbers of items	Missing (%)	Mean (SD)	Internal consistency Cronbach's α	Floor and ceiling effects (%)		Test–retest reliability (N = 36)	
							Spearman's ρ	p
Mobility	6	2	4.28 (0.92)	0.93	0.8	36.0	0.84	<0.001
Energy	3	2	3.36 (1.45)	0.92	11.1	29.4	0.67	<0.001
Upper extremity function	5	0.5	4.28 (1.04)	0.93	1.6	43.7	0.94	<0.001
Work and Productivity	3	1	4.21 (1.07)	0.92	3.2	47.6	0.94	<0.001
Mood	5	2	3.93 (1.05)	0.84	1.6	27.8	0.84	<0.001
Self-care	5	0	4.46 (0.93)	0.92	2.4	54.8	0.89	<0.001
Social roles	5	3	3.29 (1.30)	0.91	7.1	15.9	0.80	<0.001
Family roles	3	2	3.96 (1.19)	0.83	2.4	38.9	0.79	<0.001
Vision	3	0	4.58 (0.75)	0.79	1.6	62.7	0.35	<0.05
Language	5	0.3	4.59 (0.70)	0.91	0.8	56.3	0.74	<0.001
Thinking	3	2	3.79 (1.19)	0.83	3.2	32.5	0.65	<0.001
Personality	3	2	3.99 (1.18)	0.87	2.4	41.3	0.83	<0.001
SS-QOL total	49	1.4	4.09 (0.80)	0.97	0.8	8.8	0.89	<0.001

Table 4. Standard error of measurement (SEM).

Mobility	0.24
Energy	0.41
Upper extremity function	0.27
Work and productivity	0.30
Mood	0.42
Self-care	0.26
Social roles	0.39
Family roles	0.49
Vision	0.35
Language	0.21
Thinking	0.49
Personality	0.42
SS-QOL total	0.14

one SEM represents the smallest margin that can indicate a minimally clinically important difference.[42] As expected, the minimally required change scores were higher for the domain scores than the SS-QOL total score. These values that can be used as guidance in studies investigate change over time.

Construct validity

The correlations between the SS-QOL scale and the criterion-related measures are presented in Table 2, as are the hypothesized directions and magnitudes. As many measurements had ordinal scales and a few criterion-related variables were based on a single item, an ordinal correlation metric was preferred. All observed coefficients corresponded with the hypothesized correlations.

Discussion

This study examined the psychometric properties of the Norwegian version of the SS-QOL scale. The reliability, in terms of consistency and test–retest stability, was good. The construct validity was also supported, as the SS-QOL total and domain scores correlated as expected with the criterion-related measures.

Validity

The COSMIN panel defines validity as 'the degree to which an instrument truly measures the construct it purports to measure'.[43] Validity is a broad concept that can be distinguished into content, criterion and construct validity in the context of questionnaire validation.[41] Determining the content validity of the SS-QOL involved a subjective critical evaluation of whether the SS-QOL items reflected a representative selection of indicators measuring the intended concept. The content validity of the SS-QOL has been well documented by others[11] and was not re-evaluated here. Rather, we focused on the construct, or more specifically, the criterion validity of the SS-QOL by examining whether it was positively correlated with the EQ-5D sum score, specific EQ-5D domains, EQ VAS and QOLIBRI-OS as expected (convergent validity) and negatively correlated with the HADS total score and HADS depression score (divergent validity).[41]

Convergent and divergent validity. The SS-QOL scale is a comprehensive measurement, and as recommended in the COSMIN guidelines,[22] we hypothesized the magnitudes and directions of the correlations for all the specific domains and for the total SS-QOL scale against related measurements. The Vision domain had a lower correlation than estimated, whereas all other correlations were as expected or higher than expected, supporting the construct validity of the questionnaire (Table 2).

Reliability

Internal consistency. The reliability, or internal consistency, of the domain and total SS-QOL scores were high. The degree of consistency reported in this study was comparable and slightly higher than that reported by Williams et al.,[11] Muus et al.,[14] and Hsueh et al.[18] Of the 12 domains, 7 had alpha values >0.90. The observed differences were most likely related to variances in sample size and sampling procedures. Our study included more participants than the study by Williams et al.,[11] for example, and likely a more heterogeneously composed sample than those of the abovementioned studies. Most of the participants had mild- or moderate-severity stroke, similar to corresponding studies.[11,14] However, our study did not exclude persons with more severe stroke, with aphasia and/or cognitive problems or with comorbidities. Our more heterogeneous sample may partly explain the higher alpha values.[41] According to de Vet et al.,[41] Cronbach's alpha values above 0.90 may indicate redundancy of items and suggest the need to shorten the scale. However, since the domains of the SS-QOL scale consist of three to six items, we would not recommend this approach.

Test–retest reliability. The test–retest reliability of the SS-QOL was satisfactory, with only three domains showing values below 0.7 (Table 3). Other SS-QOL validation studies using the same test–retest timeframe (1–2 weeks) displayed correlations from 0.71 to 0.96[16] and 0.65 to 0.99.[14] The Vision domain was again problematic, showing the lowest test–retest correlation with Spearman's rho of 0.35 ($p < 0.05$). One of the items 'Did you have trouble reaching for things because of poor eyesight?' might have been ambiguous to the participants, as it may convey two meanings: physical problems with reaching for items independent or dependent of eyesight. 'Trouble reaching for things' after a stroke can be related to sensory motor deficits or other perceptual and cognitive impairments such as apraxia, agnosia, neglect or other visuospatial challenges. It may be difficult for persons with stroke to establish the reason why they are experiencing difficulties. As some of the included participants reported vision problems, this health problem should not be overlooked, and a future approach may be to improve the clarity of this question. The psychometric properties of the Vision domain were not satisfactory, and we suggest rephrasing at least one of the three items and then re-validating the domain.

The Energy and Thinking domains also had test–retest coefficients below 0.7, which may reflect a true day-to-day fluctuation (e.g. the need to rest, various levels of ability to concentrate) rather than an unreliable domain, as Cronbach's alpha values were satisfactory. The high reliability and the low SEM scores in several of the domains in our study, all below 0.5 SD, indicate that the SS-QOL scale is highly suitable for assessing individual participants' HRQOL, as well as in researching HRQOL among stroke survivors.

Quality of data. The data quality in this study was good, with a low amount of missing data. As noted by others, for example, Muus et al.,[14] the item 'I had sex less often than I would like' (Social Roles domain) had the largest number of missing responses (15%, n = 19). This item might be considered less relevant or too sensitive or private for some of the participants. Another item, 'change in personality' (prior to stroke), was also often incomplete. Personality changes can be difficult to assess by the individuals themselves, or the question might be too sensitive to answer. Another possibility, also noted by Muus et al.,[14] is that the layout of the questionnaire, with this particular item separated from the others, could make it easier to overlook. Overall, the high data quality indicated that the SS-QOL questionnaire was understandable and easy to complete.

Floor/ceiling effects. Less than 9% of the total SS-QOL scores exceeded the ceiling threshold, which may be considered acceptably low. The ceiling effects of the domain scores were higher but on par with previous findings,[11,14,18] ranging from moderate to high. A ceiling effect was particularly present for the Vision domain (62.7%), as Muus et al.[14] also reported. The variations in ceiling effects reflected areas that were more or less affected by stroke. The observed ceiling effect in the Vision, Language and Self-Care domains may indicate that these areas are less frequently affected among the responders in this stroke population.

As persons with stroke are a heterogeneous group with various and different degrees of symptoms, some degree of ceiling (or floor) effects is expected. These effects may be problematic because they weaken the ability to distinguish participants in the higher (ceiling) or lower (floor) levels of the construct, whereas the middle area is less affected. However, a high score within an SS-QOL domain simply reflects normal functioning within this area, and according to de Vet et al.,[41] when a large proportion of the population has no functional problems, it should not be considered a ceiling effect. In contrast, a lower score may indicate a particular functional problem within a domain. Due to the considerable heterogeneity in the symptoms and functional consequences of stroke, ceiling (or floor) effects are normally more present in domain scores than the total score, and thus, the total score is more suitable for measuring changes in the follow-up period than the domain scores.

Limitations and strengths of the study

As reported in previous studies,[11,14] most of the respondents had mild to moderate stroke. Although some eligible stroke survivors were lost due to administrative errors, we consider the study population reasonably representative for measuring HRQOL following stroke.

The convergent and discriminant validity, as indicators of construct validity, is a strength of the study, which tested predefined hypothesis and expected associations among similar and dissimilar measures as recommended in the literature.[40,41] For two domains in our study, the only available option was to correlate the SS-QOL domain with a single-item question from the Norwegian National Stroke Register. It could be argued that these questions are not as valid as a validated questionnaire, though the directions of the correlations were as expected in these occasions as well. Our choice of measurements did consider respondent burden, and we thus chose measurements that were practical, not too extensive, and appropriate for HRQOL assessment post stroke in this population.

Examining the discriminative validity of the SS-QOL using factor analytic methods was not deemed appropriate in this study due to the low subject-to-item ratio. The large number of items and particularly the large number of latent factors (12 domains) would require a considerably larger sample size to achieve satisfactory statistical power.[44] Due to the low power in this study to test such complex models, the risk of type II error would be unduly high. The 12-domain factor structure has previously been examined using confirmatory factor analysis in a sample of 388 stroke survivors, and the results supported the current factor model.[18]

Conclusion

The Norwegian version of the SS-QOL scale is an instrument with good psychometric properties. It is suited for use in health research as well as in individual assessments of persons with stroke.

Clinical messages

- Our results support the Norwegian version of the SS-QOL scale as an instrument with good psychometric properties.
- Construct validity of the scale is well supported.
- The instrument is applicable, understandable and easy to complete.
- The SS-QOL scale is suited for use in research as well as in assessments of individual stroke survivors.

Acknowledgements

We would like to acknowledge the participants, translators, and Neurology Departments in Norway and the physical therapists in the stroke unit in Tromsø for the systematic collection of data. S.G.P., A.A., C.A. and G.H. contributed in designing this study, analysed the data and had the overall decision-making in this study. S.G.P. and G.H. were responsible for producing the data. A.A., C.A. and O.F. contributed with supervision on the overall use of methods, the data analysis and interpretation of data. O.F., J.F.N. and H.H. overlooked statistical analyses and interpretation. S.G.P. drafted the manuscript and all authors contributed to critical revision of the article.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

This study was conducted according to the Helsinki Declaration regarding informed consent and confidentiality. The Regional Norwegian Ethical Committee Health Region North approved the study (2013/1461).

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Northern Norway Regional Health Authorities funded this work (grant no. SFP1174-14).

Informed consent

Patients were informed about the study by nurses in the stroke units or by health professionals responsible for updating the information in the Norwegian National Stroke Register. Written informed consent was obtained from all the participating subjects before study initiation. Each hospital had one to three local health professionals who collected all the data.

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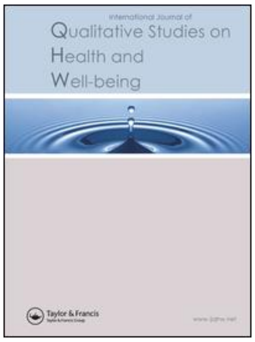
PAPER II

Synne Garder Pedersen, Audny Anke, Lena Aadal, Hanne Pallesen, Siri Moe, Cathrine Arntzen. ***Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis.*** International Journal of Qualitative Studies on Health and Well-being 2019; 14:1



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International Journal of Qualitative Studies on Health and Well-being

ISSN: (Print) 1748-2631 (Online) Journal homepage: https://www.tandfonline.com/loi/zqhw20

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To cite this article: Synne G. Pedersen, Audny Anke, Lena Aadal, Hanne Pallesen, Siri Moe & Cathrine Arntzen (2019) Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis, International Journal of Qualitative Studies on Health and Well-being, 14:1, 1659540, DOI: 10.1080/17482631.2019.1659540

To link to this article: https://doi.org/10.1080/17482631.2019.1659540

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH AND WELL-BEING
2019, VOL. 14, 1659540
https://doi.org/10.1080/17482631.2019.1659540

Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis

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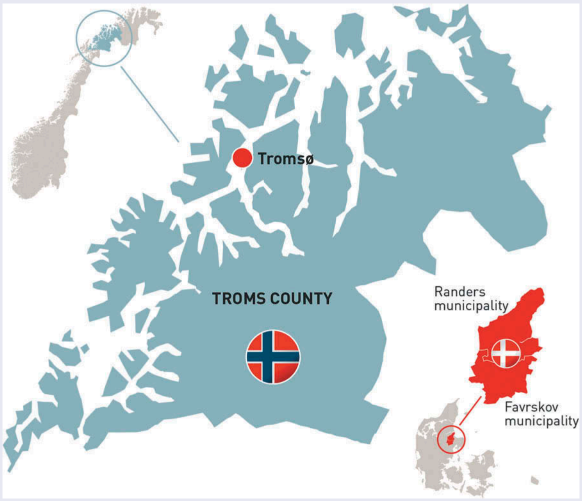
ABSTRACT

Purpose: This study aims to explore quality of life (QOL) during the first year of recovery after stroke in North Norway and Central Denmark.
Method: Individual in-depth interviews with 11 stroke survivors were performed twelve months after stroke onset. An interpretative, inductive approach shaped the interview process and the processing of data.
Results: We found that QOL reflected the individuals' reconstruction of the embodied self, which was identified by three intertwined and negotiating processes: a familiar self, an unfamiliar self, and a recovery of self. Further, we found that reconstruction of the embodied self and QOL could be framed as an ongoing and interrelated process of "*being, doing, belonging and becoming*". Enriching social relations, successful return to work, and continuity and presence in professional support during recovery enhanced the experience of QOL. Fatigue and sustained reduced function hindered participation in meaningful activities and influenced the perceived QOL negatively.
Conclusions: The two countries differed in descriptions of continuity and support in the professional follow-up during the recovery process, influencing the degree of encouragement in reconstructing the embodied self. Reconstruction of the embodied self is a means of understanding stroke survivors' QOL during the first year of recovery, supporting an individualized and tailored rehabilitation practice.



ARTICLE HISTORY
Accepted 19 August 2019

KEYWORDS
Quality of life; stroke; recovery; self; embodiment; fatigue; qualitative research

Introduction

This study explores quality of life (QOL) one year following stroke in a region of North Norway and in the Central Denmark Region. The two Scandinavian countries are both fairly equivalent welfare societies and have similarities in life expectancy rates and cultural aspects. Geographically, different regions in North Norway are very dissimilar to Denmark, with large areas and scattered settlements. Consequently, distances to hospitals and other medical and rehabilitation centres are longer for the North Norwegian population, and some variances in health organization exist in terms of small (North Norway) and large (Denmark) units. These differences, along with

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local available resources, e.g., specialized professionals and individual and cultural variations in understanding rehabilitation and illness, may be important for quality of life during recovery after stroke. This study will be relevant for gaining insight into potential differences and similarities in the experienced quality of life during the first year of recovery and between two country regions after stroke.

QOL is central in stroke rehabilitation, wherein optimizing functions or adaptations to everyday life are common essential goals shared by stroke survivors and professionals (Wiklund, 2004). However, QOL is a broad and multifaceted phenomenon that may convey many meanings (Dijkers, 1999; Farquhar, 1995; Hill, Harries, & Popay, 1996; Post, 2014). Studies have implied a connection between physical function and QOL, but the results vary, with some studies implying a connection while others do not (Carod-Artal & Egido, 2009; Carod-Artal, Egido, González, & Seijas, 2000; Gunaydin, Karatepe, Kaya, & Ulutas, 2011; Samsa & Matchar, 2004; Suenkeler et al., 2002). Other studies find that QOL is a complex phenomenon that embraces more than merely physical functioning (Clarke & Black, 2005; Green & King, 2009; Kirkevold & Wyller, 1999). Although many studies have investigated QOL and its impacting factors, we have not found studies exploring QOL as experienced by stroke survivors across health-care systems and cultures. In this study, our understanding of QOL was framed through the World Health Organization's [WHO] definition: 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment' (World Health Organization, 2018). This definition is broad and sufficiently open for empirical exploration of different aspects of the phenomenon as experienced by stroke survivors themselves.

Stroke may cause a variety of impairments, which have long-term physical, cognitive, psychological and social consequences for approximately one-third of survivors (Wolfe et al., 2011). Recovery after stroke is described as a dynamic process in which patients' outcomes are heterogeneous and characterized by individual recovery patterns (Langhorne, Bernhardt, & Kwakkel, 2011). Several studies (Arntzen, Borg, & Hamran, 2015; Clarke & Black, 2005; Kitzmüller, Häggström, & Asplund, 2013; Meijering, Nanninga, & Lettinga, 2016; Pallesen, 2014; Sarre et al., 2014) have described different trajectories, patterns and transitions during recovery following stroke. Recovery is understood as a complex and transformative process influenced by varied and multifaceted individual and contextual interrelations. The process of recovery includes improvements in or adjustments to physical and cognitive impairments, as well as emotional and psychological post-stroke deficiencies. Therefore, recovery following stroke may be comprehended as an embodied and situated phenomenon as we experience our body in various ways depending on the context (Damasio, 1994; Merleau-Ponty, 1962). Throughout the recovery process, new meaning and purpose in one's life that grows beyond the persisting challenges and symptoms after stroke may develop, and recovery may involve an adaptive or adjusting process, as well as achievement of the former level of functioning (Deegan, 2002). Numerous studies have investigated experiences of recovery and life following stroke (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Lamb, Buchanan, Godfrey, Harrison, & Oakley, 2008; Lou, Carstensen, Jørgensen, & Nielsen, 2017; Murray, Ashworth, Forster, & Young, 2003; Peoples, Satink, & Steultjens, 2011; Salter, Hellings, Foley, & Teasell, 2008; Sarre et al., 2014; Wiles, Cott, & Gibson, 2008). These studies address different understandings, impacts, challenges and consequences of stroke from the perspectives of stroke survivors, thus, studies comparing experiences of recovery during the first year across health-care systems and cultures are scarce.

Variability in QOL (Sprigg et al., 2012), and recovery patterns between Western countries post-stroke (Ayis et al., 2015) are not fully understood; however, differences in cultural factors, health systems and available resources have been suggested (Ayis et al., 2015). Although several studies have documented different perspectives of QOL and recovery following stroke, we have not found studies investigating stroke survivors' *experiences* of QOL in the recovery process across countries. This study aims to explore stroke survivors' experienced QOL during the first year of recovery in North Norway and Central Denmark.

Materials and methods

Design

This interpretative, inductive study is part of the multi-centre 'NORDA-study' describing and comparing stroke pathways in a region of North Norway and the Central Denmark Region. Individual semi-structured in-depth interviews (Kvale, 2007) with stroke survivors were conducted one year following stroke. Hermeneutic epistemology (Gadamer, 2004) can describe the interpretation of text and the transformation back into meaning. In this process the researchers' interpretations involves their own interactions and experience with the world; their preconceptions are implemented in the hermeneutic phenomenological process to gain a deeper understanding of the investigated phenomenon. The dialectic movement between the text, participant and ourselves was used to seek an alternative means of interpretation rather than an illustration of a subjective point of view regarding QOL. The phenomenology of the body constituted the epistemological basis for exploring the QOL phenomenon. In this study, the lived body is understood to be situated in a dynamic physical and social life-world, implying that perception, action, awareness and emotions binds the body to the world (Damasio, 1994; Merleau-Ponty, 1962; Weiss & Haber, 1999). This overall frame of reference is useful for exploring QOL and how this phenomenon unfolds in stroke survivors' physical, practical and social situations during the first year of recovery.

Participants

The participants were identified stroke survivors living in comparable population-sized regions in the two countries and recruited by health personnel in hospitals. Adult participants were eligible for this study if they had a clinically confirmed diagnosis of ischaemic or haemorrhagic stroke and had physical and/or cognitive impairments requiring further rehabilitation after discharge from a stroke unit. Other inclusion criteria were that the participants had lived an independent life prior to stroke and were discharged to their homes after rehabilitation. Stroke survivors with cognitive or communicative impairments preventing them from sharing their experiences through interviews were excluded. At the time of the interviews, the age range was 35–66 years. They all lived in their own apartments or houses. Participants from Norway (n = 5) were discharged to five different municipalities, while the Danish participants (n = 6) were discharged to two municipalities (Table I).

Ethical considerations

The study was conducted according to the Helsinki Declaration regarding informed consent and confidentiality. The study was approved by the Regional Norwegian Ethical Committee, Health Region North (2013/1461) and the Danish Data Protection Agency (1-16-02-66-14). Written informed consent was obtained from all included participants prior to commencing the study.

Data collection methods

Semi-structured interviews with stroke survivors were conducted by the authors (S.M., C.A., L.Aa., H.P.) shortly before discharge from the hospital and three and 12 months after stroke onset. The present sub-study involves the interviews conducted approximately one year following stroke. The interview guide was developed through collaboration among the authors and included topics on experiences and reflections regarding perceptions of life and the recovery process. The interviews (n = 11) ranged from 60 to 90 minutes and were audiotape-recorded with the participants' permission. Carers were sometimes present during the interviews, and since some participants had problems with memory and/or speech, their contributions were important and helpful. All interviews were conducted in the participants' homes or workplaces and were transcribed verbatim with identifying data removed.

Analysis

The interdisciplinary researchers in this study have extensive experience in stroke rehabilitation. Professional competency is a key prerequisite for knowledge development, but potential may exist to make quick decisions without ruminating sufficiently on the participants' experiences. Therefore, we carefully discussed our interpretations and challenged our preconceptions through systematic reading of the interviews and repeated discussions among the research group. Theory and research in the field were also important for implementing our pre-understanding and attaining a deeper understanding of the meaning structures in the participants' QOL. Through systematic shifts between deductive analytic parts, the material as a whole and literature, interpretation was developed through multiple stages of understanding—the hermeneutic circle. Data were reconceptualized in an analytic text with stories, patterns and variations that shed light on the research question. The alternation between empirical data and theory reinforced the distance to the material.

An inductive approach through systematic text condensation (STC) was used (Malterud, 2012). This approach is a pragmatic procedure inspired by Giorgi's psychological phenomenological analysis. STC is a systematic, descriptive and explorative method for thematic cross-case analysis for qualitative data, involving analytic reduction with specified shifts between

Table I. Sociodemographic data

Case	Gender	Age	Country	Marital status	Work post stroke	Residents in municipality
1	Woman	<60	Denmark	Cohabiting	Retired	61.000
2	Man	≥65	Denmark	Cohabiting	Retired	61.000
3	Man	<50	Denmark	Cohabiting	Fulltime	61.000
4	Woman	<40	Denmark	Cohabiting	Work-training	48.000
5	Woman	<55	Denmark	Cohabiting	Work-training	48.000
6	Man	<55	Denmark	Cohabiting	Work-training	48.000
7	Man	<50	Norway	Single	Work-training	4.800
8	Man	<70	Norway	Single	Retired	72.000
9	Woman	<50	Norway	Single	Retired	9.500
10	Man	<45	Norway	Cohabiting	Work-training	3.500
11	Man	<60	Norway	Cohabiting	Retired	5.500

de- and re-contextualization of data (Malterud, 2012). The data were processed in NVIVO 11, where all meaning units were identified and abstracted through condensed meaning units and code-groups. The coding was discussed with last-author (C.A.) to reach a consensus regarding subgroup priority. Meaning units within the same subgroup were reduced into condensates uniting the content of the meaning units from the subgroups. A reflexive journal and a matrix for the data analysis were developed and further used as a basis for developing categories and themes. Descriptions and concepts were developed by synthesizing the contents of the condensates. The re-contextualization with interpretation and findings was systematically assessed and validated against the initial complete transcripts. Throughout the critical analysis, we asked questions: What does this mean? What is this similar to or different from? Then, similarities and differences were compared. We searched for theoretical concepts that could provide new understandings of the stories told by the participants. New interpretations emerged through literature and research on the embodied self (Gallagher, 2011; Weiss & Haber, 1999). The presented analytic text represents the most salient content and meaning that emerged from the empirical data (Figure 1, Table II). Relevant quotations are embedded in the analytic text to provide additional illustrative text elements.

Results

QOL and reconstruction of the embodied self

Stroke was experienced as a discontinuity in life, which essentially changed the story and conception of who they were. We found that QOL as experienced during the first year after stroke reflected a reconstruction of the embodied self. At stroke onset, unfamiliarity with the self was prominent as functional deficiencies initially represented a temporary discontinuity of self and a known way of being in the world. The experience of QOL was embedded in the *recovery of self* that gradually moved towards *a familiar self* one year following stroke (Figure 2). For a few participants, continuity of self-reconstruction was hindered due to the stroke experience and the internal battle between a familiar and *an unfamiliar self*. This intertwined and negotiating reconstruction process was essential to the person's QOL, and will be outlined below.

The familiar self

The narratives led to different descriptions of "I can" or "I cannot" and referred to the subject's body and ability to move, perceive, reflect and be aware. The individuals' possibilities in life was important for different aspects of valued activities, social participation and QOL. The participants who had restored all or most of their function reflected upon a returned normality—both generally in life and themselves as a person. A woman from Denmark provided the following statement:

> *'There are no changes in my everyday activities, and I am doing the things that I did prior to my stroke. Basically, I am back to the person I used to be.'* (case 1)

Those who no longer experienced restrictions in functioning described a continuous positive change in their self-awareness during the first year following stroke. The descriptions revealed that earlier functional disruptions, whether to the emotions or to the body, came to the foreground of awareness in different situations. Several of the participants mentioned how they used to think about *how to* do basic things in the early phase, i.e., walking, cleaning or cooking, whereas these activities were now executed pre-reflectively without thinking about or planning the corresponding actions. Self-awareness disappeared to the background as they progressed. A man from Denmark elaborates:

> *'My grocery-shopping may take a little more time … ., but no—I don't even know if it does. I am not speculating about it anymore.'* (case 2)

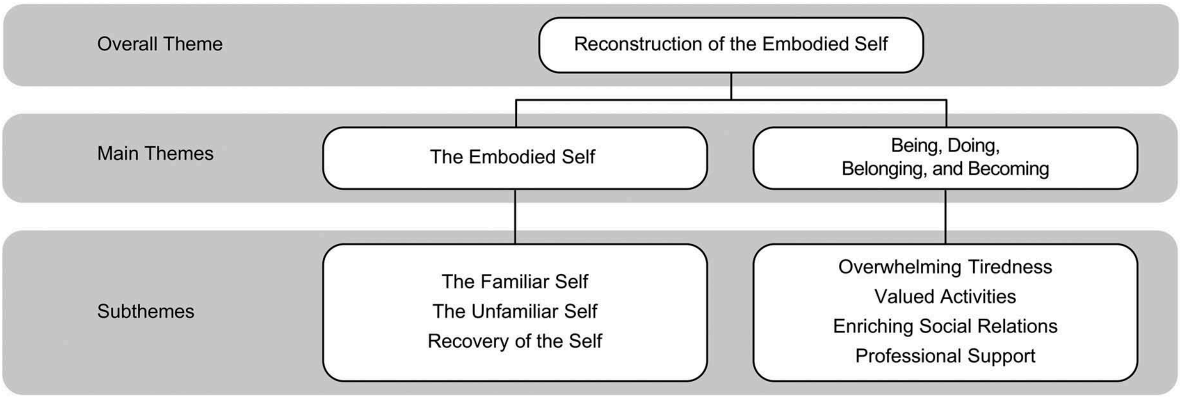

Figure 1. Illustration of emerging themes.

Table II. Systematic process of de-contextualization and re-contextualization. Shortened example of data analysis. Conversation about ADL-activity and whether there are specific things that will not succeed when it comes to function

Meaning units and possible key quotes withdrawn from condensates	Code group	Condensates	Sub-category	Category	Theme
"(…) Basically, I am back to the person I used to be"	**Bodily changes and identity**	I think it´s going well, really. For the most part, I function the way I used to. I don´t think about activities that may not be done in in the same way anymore. If there are any, they are just unconsciously done in a different approach. There are no changes in my everyday activities, and I am doing the things that I did prior to my stroke.	Managing everyday activity Independence	Normality Back to being me	**A familiar Self**
"As long as you walk around 'partial', it affects you"		My life is turned upside-down, and I have to ask for help. I used to be a handy-woman, and it feels so weird not to be able to do things myself. It is a new role and I constantly dread the fact that I need to ask for help. I used to be a very social person, and now I´m afraid to go out because I can´t talk to that many people. I have to think and do things differently than I did before, and this makes me very sad—I don´t even know how to explain this. She needs to adapt another life-situation that is not her. Even though we still see glimpses of her, she is another person now. The fact that I can´t remember names disgusts me. Sometimes I start doing things automatically, and suddenly I realize that I can´t do this anymore—and this makes me furious and annoyed.	Loss Alienation Dependency	Unfamiliarity Changed perception of self	**An unfamiliar Self**
"I have accepted the situation for what it is, and I don´t get annoyed or depressed by anything now"		I have lost the overview in terms of following up on our practical things, and my wife is now the man in the house. Initially I thought it was terrible for myself that I could not continue doing my work, that I was good at, and the loss off my familiar co-workers. I used to take part of conversations and discussions in groups of people, but now I can´t be bothered. Earlier in the process I used to get very sad when people asked about, or responded to, the way I talked—and now this does not bother me at all. Previously I could not accept that I had to let go of my regular work. Right now, I don´t feel that I had to let go of anything.	Social re-positioning Resignation Accept	Processes of ● adjustment ● re-establishment of an adapted self Ambivalence in the process	**Recovery of Self**

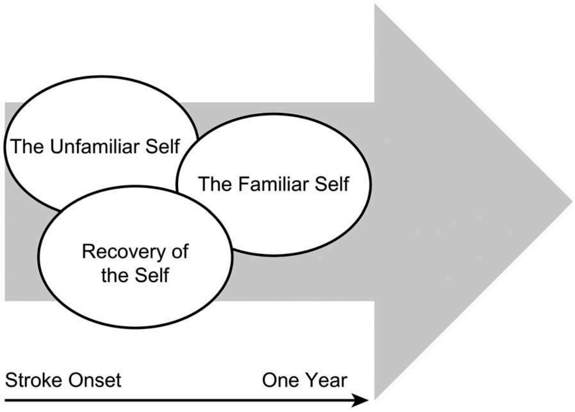

Figure 2. Intertwined and negotiating processes in the embodied self following stroke.

The embodied knowledge in "how to do things" and the "I can" without too much struggle or thinking brought back normality and a familiar self. Descriptions from several Danish participants were portrayed as especially successful in terms of a sustained or re-established familiar self, and the same participants described a high degree of functioning and QOL. None of the Norwegian participants described the same success in regaining normality or familiarity in the embodied self.

The unfamiliar self

Some of the participants struggled with not being who they used to be familiar with and repeatedly referred to themselves as the person before and after the stroke. Functional problems disturbed a known, familiar way of doing things and living life, thus affected their experienced QOL. In contrast to the above examples, the functional disruption and the awareness about themselves was still in the foreground in their lives. Every time they struggled in a task or in a situation, the body made itself apparent, and the awareness about what they could not achieve asserted its presence. Some participants found their functional interruption, e.g., memory loss or speech problems, repulsive because it contrasted with the image of the person that they identified themselves with—the familiar self. The breach in sense of self persisted for those who struggled with function in a profound manner and interfered with their QOL. For these participants, reconstruction of the embodied self did not progress in a positive direction after stroke. A woman from Norway claimed that her life and what she could do had changed overwhelmingly after her stroke, affecting her perception of herself. Her valued independence had turned to dependency, and her very active social life and social interactions had become challenging:

> *'My life is turned upside-down, and I have to ask for help. I used to be a handy woman, and it feels very weird not to be able to do things myself. It is a new role and I constantly struggle with the fact that I need to ask for help. I used to be a very social person, and now I am afraid to go out. I have to think and do things differently than I did before, and this makes me very sad—I do not even know how to explain this. I do not know if I will ever accept this situation. (…) I am basically dependent on others. I do not feel free—not the way I used to be.'* (case 9)

Some participants struggled to accept the breach in who they used to be in the world, and the new circumstances were parts of the self was unfamiliar because of different functional problems that ultimately changed their QOL. Participants from both countries described unfamiliarity in life and self, but only the Danish participants described receiving professional help to sustain their self-constructing process by focusing on unfamiliar aspects of self.

Recovery of the self

Some of the participants recognized their persistent functional problems and talked about acceptance and adjustment to the new situation. The acceptance and adjustments increased the participants' experience of QOL. Numerous participants from both countries told stories about the changes that they had been through and described the alteration from feeling sad, upset, annoyed, anxious or depressed (early in the process) to not responding in this manner at all to their present functional problems. Adjustment and acceptance gradually moved forward to a more settled, adapted embodied self.

> *'Previously, I could not accept that I had to let go of my regular work. Right now, I do not feel that I had to let go of anything.'* (case 4)

Several participants from both countries seemed to be able to re-establish an adapted self and a form of new normality through their acceptance and despite their losses in valued activities and social involvement. Although some described an ambivalence in their acceptance of certain embodied changes:

> *'I have accepted my situation, but it is sometimes hard for me to accept that I cannot accommodate the outlook that I had before.'* (case 4)

Recovery of the embodied self illustrates a process interconnected with acceptance, progress, adjustments and management in life. Despite persistent functional problems, most of the participants were able to put their experience of stroke in perspective one year later, and several participants expressed gratitude for the currently regained QOL.

QOL and dimensions of being, doing, becoming and belonging

Reconstruction of the embodied self can be understood as an ongoing and interrelated process of "being, doing, belonging and becoming" (Hitch, Pépin, & Stagnitti,

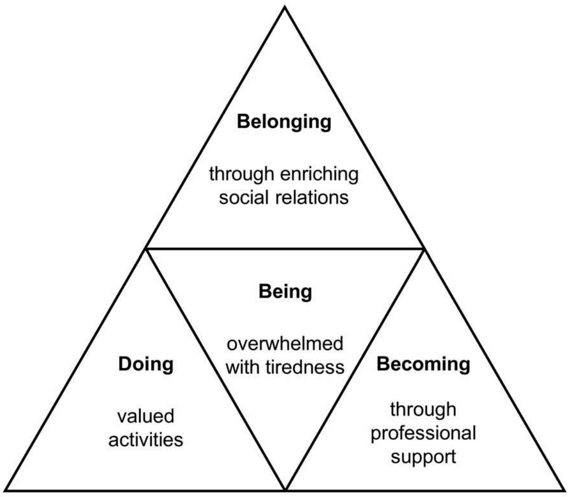

Figure 3. Interconnected aspects relevant for reconstruction of the embodied self.

2014a, 2014b; Wilcock, 1998, 1999). These aspects conceptualize *being* as humans and may provide an understanding concerning essential human desires and possibilities significant for QOL. In this study, we found that *being* is linked to doing (action or engagement), belonging (relationships and connectedness) and becoming (a perceptual process of change and development). Thus, bodily changes or disruptions could interfere with these dimensions and affect QOL (Figure 3).

Being overwhelmed with tiredness

An overshadowing consequence of persistent tiredness followed all the participants one-year post-stroke. Tiredness still influenced everyday life regardless of how well the participants had recovered. The individuals' conception of their own capacity influenced their experience of QOL. They all emphasized that such tiredness represented a change in their lives that they did not experience prior to stroke.

> *'My biggest issue right now is that I need an hour to rest in the afternoons—it is a necessity to function the rest of the day and gain some energy. It* [the tiredness] *is a little bit better now, but without my hour of rest, I will not make it through the day. It is a disadvantage in my life.'* (case 2)

All of the participants talked about changed capacity or energy levels in relation to other people, work and leisure activities Almost everyone told stories of how they protected themselves from energy-consuming activities or participation throughout the day. The tiredness was portrayed as a disruptive phenomenon, influencing their overall existence—their *being*, hence influencing reconstruction of the embodied self and QOL. When tiredness precluded the participants from activities or social function, it impacted on how they saw themselves and how they assessed their own capacity in life through the "I can" or "I cannot". None of the participants from Norway explicitly described external support to help manage the tiredness. In contrast, the Danish participants portrayed insightful knowledge of strategies for recreation to manage in everyday life throughout the recovery process, and they expressed that professional support directed them towards compensating strategies, cognitive functioning and language barriers, all of which increased their overall capacity during the day.

Doing valued activities

Some factors threatened reconstruction of the embodied self and QOL more than others. The ability to work was particularly central to the participants' described self-worth in both countries. Work was portrayed as self-identity by most of the participants and had a profound impact on how they saw themselves, i.e., as valuable, productive and useful individuals in society. Most of the participants had a changed or reduced work status one year after injury. While a few participants articulated satisfaction with this arrangement, others clearly missed their regular jobs and expressed uncertainty, thus hope for full-time jobs again. A man from Norway who was under organized work training elaborates:

> *'It is a place with other people, and you do not just sit at home. I think the psychological perspective of being there is very important. (…) It has been a very positive experience in numerous ways. But it is not my job—nothing of what I do is me. Although, I am being useful, I can see results in my functioning and in the job, so it is positive. Still, I would like to get back to my profession, and the goal is to get back to my job—the job that is me (…) It has a lot to do with quality of life—To work with what you really like doing.'* (case 7)

The job that he had previously performed was strongly related to his embodied familiar self. Although temporary employment with unfamiliar work tasks was not what most of the participants hoped for, they generally adjusted to the situation and were pleased to contribute something in everyday life.

The ability to drive was another valued activity important for QOL. Most of the participants in both countries spoke of enhanced life quality after they had received permission to drive again. Driving licenses represented a sense of freedom and an opportunity to pursue other valued activities. Some participants did not have permission to drive one year following stroke and explicitly described how this affected their QOL. A Norwegian man who lived in a rural area and had few options for public transportation expressed his situation as follows:

> *'If it continues like this, without permission to drive, I will bore myself to death. (…) The most important thing for me right now is to get my driver's license back*

> *so that I can continue doing the things that I used to do.'* (case 11)

Some of the Norwegian participants described isolation without their driving licenses because they lived in sparsely inhabited areas, while others who lived more centrally described restrictions in their possibilities and the sense of freedom that driving a car may supply. Restricted permission to drive influenced a few of the participants' work situations and the possibility to proceed in their profession as a professional driver. Hence, being able to work and drive again was important for the experience of QOL.

Belonging through enriching social relations

Interactions and continual close relationships with family, friends, neighbours and co-workers emerged as an essential aspect for reconstruction of the embodied self and QOL. Engaging in social relationships implied incorporating others into the self and appeared important for regulating behaviour and sustainment as a person following stroke. The extent of social relationships was different in each case, but all participants highlighted the importance of having some sort of social relations. Close family was described by several of the participants as especially valued in the process of recovery. Spouses, cohabitants, children or friends had become even more important to the participants after stroke, and were natural facilitators in adjusting to everyday activity. The participants' loved ones similarly needed to adapt to a new situation, and adjustments after stroke became a common concern that created strengthened relationships. A man from Denmark describes the value of his relationships as follows:

> *'To me, having a good life means that I as a person can do the things that I appreciate and love: go fishing, be with my family and my friends. Be with them in a way that is enriching to me—and hopefully for them too. Also, having a good life, most of all, is that we as a couple are doing well.'* (case 3)

Valuable interactions with peers were highlighted as important for QOL by most of the participants. Several of these stories were related to the acute hospitalization and rehabilitation units, and some of the participants still had strong connections with their peers. These relationships were referred to as social community networks in which members cared for each other. Observing and following the recovery processes of peers provided motivation and drive to push harder in the participants' own training and recovery. Several explained that they felt comfortable and safe in a group of peers. In particular, those who experienced aphasia, dysarthria and cognitive problems highlighted the importance of "mutual ground" and, in a sense, "levelling" with others undergoing the same experience. Language and memory barriers were easier to overcome when practising within a group of peers. Some of the participants explained that they did not feel judged or misinterpreted in this type of setting, and they felt comfortable practising:

> *'It means a lot, because you are allowed to speak without the comments of 'what is he talking about?' or an obvious shutdown in communication—because these people are in the same situation. It is good training, and good rehabilitation.'* (case 2)

In the Central Denmark Region, most of the participants appreciated the group training or special conversation groups with peers throughout the one-year process. In North Norway, none of the participants had stories that included peers while being followed up in the municipalities. The narratives indicated that peers were important for recovery, as well as established, continuous friendships across age groups and genders outside of organized group activities. Peers were referred to as a community of "us", and they shared a collective *belonging* that helped them make sense of the world due to their common experiences. We found that belonging through enriching social relations had a positive influence on reconstruction of the embodied self and QOL.

Becoming through follow-up and continuity in professional support

The initial recovery process during hospitalization and subacute rehabilitation was portrayed as a mainly positive experience for the participants. In this period, they typically experienced rapid progress in their function, and several of the participants highlighted the value of intensity in training, knowledgeable health personnel and good relations with peers and professionals.

When returning to their homes and undergoing follow-ups in the municipalities, a discrepancy was noted in how the participants described the continuity and follow-up by health professionals and how this affected their process of recovery and QOL. Participants from Denmark indicated that they received good care within the system, while most participants from Norway described discontinuity and insufficient follow-up. The participants reported that structural and organizational differences between health-care systems had an impact on QOL in several ways. For most of the participants, a close, continual follow-up was important for function, independence and return to "familiarity" and QOL, while for others, it was important for feeling safe and taken care of within the system.

In the Central Denmark Region, most of the participants described relatively continuous transitions between the health-care levels, and a system that worked optimally with very good support and help every step throughout the journey. Other participants from Denmark noted that the long-term continuity in follow-up services had provided them a smooth transition back to "normality" and the familiar self, influencing their experience of QOL.

> *'It is the process in itself, the long-term plan that was made for me in the beginning, that has brought me back on my feet again. My life has become reasonable again.' (case 2)*

Most participants from North Norway described both an absent and incoherent follow-up by professionals in the communities. Transition periods between health-care levels were especially vulnerable; they did not describe seamless shifts, but rather disturbing breaks in transitions that affected their QOL. Most of the descriptions were related to the shifts between specialist health services (i.e., hospitals) and follow-up services in the municipalities. Another topic was vulnerability in the small municipalities related to professional follow-ups during holidays and sick-leaves, which could result in weeks or months without any training. Specificity in training was another concern. Thus, the participants from North Norway requested both quantity and quality in their follow-ups. One Norwegian participant related the lack of intensity and the discontinuity in professional support directly to his slow physical recovery and QOL. Months after his initial hospitalization, he was granted a stay in a rehabilitation institution that allowed an important transformation in his recovery:

> *'Of course, it would have helped me* [more treatments in the municipality]. *I saw what a three-week stay in a rehabilitation institution did for me. In 14 days, I doubled the strength in my hand.'* (case 11)

The participants related professional support to how they managed one year following stroke and their overall QOL. Participants from North Norway described a lack of municipal follow-up regarding several aspects to facilitate recovery towards a new everyday life. Another consequence was that the Norwegian participants did not portray a holistic recovery that matched that of the Danish participants. We found strong relationships between stories of person-centred approaches, continuity of support and reconstruction of the embodied self. The substance and continuity of professional support may therefore be of great importance to stroke survivors' *becoming* by facilitating an individualized and tailored practice that supports reconstruction of the embodied self, hence accelerates the experience of QOL.

Discussion

How stroke challenges the embodied self and being in the world

The unfolding phenomena of QOL during the first year following stroke in North Norway and in the Central Denmark Region can be described by three different, entangled, embodied processes of reconstructing the embodied self. We identified these processes as *the familiar self, the unfamiliar self* and the *recovery of self*. We demonstrated that reconstruction of the embodied self was related to progress in functional recovery or adjustments for engaging in meaningful activities in life, which was important for QOL.

Previous studies have highlighted QOL as a negotiation of self and identity (Clarke & Black, 2005; Moeller & Carpenter, 2013). However, the findings of our study illustrate the interrelations between body, self and QOL in the unfolding recovery process after stroke. Embodied self in this study is understood as an interwoven relationship of body and self, where embodiment plays a central role in structuring experience, cognition and action (Gallagher, 2011). Our findings indicate that bodily changes influence an individual's embodied self as others have also suggested (Kitzmüller et al., 2013; Pallesen, 2014; Timothy, Graham, & Levack, 2016). Studies have described recovery after stroke as a negotiation trajectory between body, self and participation in everyday life (Arntzen et al., 2015; Arntzen, Hamran, & Borg, 2015). Yoshida (1993) previously described the impact of chronic illness on self among adults with traumatic spinal cord injury. As in this study, the familiar self (conceptualized as the former self) refers to the pre-injury embodied self-concepts of an individual, which forms the basis for reconstruction of the embodied self.

Quality of life—an integrated process of being, doing, belonging and becoming

We demonstrated that the negotiating processes of embodied selves were closely related to the individuals being, doing, belonging and becoming: Possibilities, relationships and support were significant for how the embodied self and QOL were perceived. The experienced differentiations and contextualization in reconstructing an embodied self after stroke are described less extensively in the literature, although Timothy et al. (2016) described a fluctuation of divergence and cohesion in the relationship between body and self following stroke.

Being

Although fatigue is common immediately after stroke, tends to persist and contribute to lower QOL (Wu, Mead, Macleod, & Chalder, 2015), only the Danish participants described how professional support made their *being* easier through structured plans and coping strategies for managing on a daily basis. Previous authors (Meijering et al., 2016) have implied that stroke rehabilitation services should address the individual and everyday challenges to improve well-being. More research to understand destructive post-stroke phenomena, such as fatigue, has been requested to identify effective methods to help stroke survivors gain wholeness of body and self (Kitzmüller et al., 2013). Our findings indicate that professional support aimed to render different activities less time-consuming and demanding to prevent tiredness from taking up too much of the individual's total capacity in everyday life, may support reconstruction of the embodied self and QOL through a more manageable *being*.

Stroke challenged several of the participants' understanding of themselves in relation to *being* through disruption of, e.g., social roles (*being* a mother, *being* a co-worker), or cultural Western aspects of *being* with individual choice and agency. *Being* is associated with the lived experience and with the embodied structures that are used to make sense of the world and one's meaningful activities, interactions or goals and to protect one's sense of basic worth (Gallagher, 2011; Leary, Tangney, & ProQuest, 2012; Wilcock, 2006). Thus, the embodied self is related to existential aspects of human *being* that acknowledge the lived experience of "who I used to be". Through the concept of *being*, fatigue can be understood as a disruption between the familiar and unfamiliar selves. Studies have highlighted the importance of intervening against fatigue (McGeough et al., 2009; Vestling, Ramel, & Iwarsson, 2013). The findings of this study illustrate the importance of reassuring how stroke survivors manage in life over time and the significance of professional support in the structure and manageability of everyday life to enhance QOL as much as possible.

Doing and meaning-making

Being is linked to *doing* by action or engagement (Hitch et al., 2014a; Lyons, Orozovic, Davis, & Newman, 2002). We showed that certain elements, e.g., work, were more important than others for the embodied self and accordingly for QOL. Returning to work has been found to be an important factor for subjective well-being and satisfaction following stroke (Vestling, Ramel, & Iwarsson, 2005; Vestling, Tufvesson, & Iwarsson, 2003). Proportionally, more time is spent on work rather than other activities (Vestling et al., 2013), and in various ways, work was an integral part of identity and "who I am" and "what I do" for several of the participants, as described by others (Brannigan et al., 2017; Kielhofner et al., 1999). Although many of the participants were content with other or different work tasks, others were very expressive in saying "this is not me". This finding emphasizes not only the importance of returning to work after stroke but also returning to previous work assignments (or other valued activities) related to self-worth and identity if this is significant to the individual. Previous studies indicated that the more a working role defines a person's identity, the more essential work is to that person (Kielhofner et al., 1999). As portrayed by Vestling et al. (2013), work has multiple subjective meanings, where self-worth and social aspects are prioritized above the economic perspective of working. For most of the participants, work was regarded as enjoyable, enriching and meaningful. Productivity, personal development and performance are aspects relevant to the self in a work setting (Brannigan et al., 2017). As addressed in our study, sustained social relationships and collective meaning-making with co-workers was another important perspective, which has also been described previously (Brannigan et al., 2017; Vestling et al., 2013).

Belonging and shared meaning

Belonging is identified with interpersonal relationships, connectedness and health (Wilcock, 2006). Enriching social relations were important for the participants' QOL. This finding has been highlighted by others, e.g., Lynch et al. (2008), who stated that maintenance of healthy social relationships may be the most important and salient influential factor on QOL after stroke. King (1996) found that social support was essential to post-stroke QOL. Our findings with many and varied narratives of support, help, strengthened relationships, motivation, unity and shared meanings in these connections, suggest that both social interactions and continual close relationships are relevant for reconstruction of the embodied self and QOL. The aspect of *belonging* is multifaceted, and an individual may *belong* to multiple, different social networks, e.g., close family and friends and more formal settings such as co-workers or groups with peers. The connectedness through shared meaning that many participants had with peers was prominent and important for reconstruction of the embodied self. This finding suggests the value of more extensive establishment of groups of peers, especially in North Norway where none of the participants had experiences of such arrangements in the municipalities.

Becoming through change and development

Our study illustrated that restoration of function and managing through functional progress or adjustments following stroke had existential value and was important for QOL. Previous studies disagree on the relationship between function and QOL (Carod-Artal & Egido, 2009; Clarke & Black, 2005; Samsa & Matchar, 2004). Our study demonstrated that the body's ability to perceive and experience the world was abruptly disrupted, creating an ambivalent relationship between the familiar and unfamiliar embodied selves. The body is anchored in familiarity (normality), thus can create new familiarity through recovery. Further, functional recovery was important for all aspects of being, doing, belonging and becoming, and all dimensions were interconnected to the embodied self and the existential *being*. For these participants, the sense of *being* was built through a sense of *doing* meaningful things. Being able to do things evolved the sense of *becoming* and sustained the sense of *belonging*, emphasizing the connectedness between function, embodied self and QOL.

The dimension of *becoming* is related to a perceptual process of change and development that depends on stimulation or feedback from others, which is captured as a "situatedness" within ongoing life (Hitch et al., 2014a; Wilcock, 2006). *Becoming* is related to a dynamic and emergent perspective on identity, which is embodied by the changing self (Wilcock, 2006). Following stroke, professional support and therapeutic relationships essentially influence the development of *becoming* in the recovery process. Becoming is not always about improvement but also about adjustment through managing and maintaining (Hitch et al., 2014a). Our study found that professional support was crucial for change and development following stroke; thus, a difference was found between the countries in continuity and sustained support by professionals, which has also been described by Arntzen, Moe, Aadal, and Pallesen (2019), Pallesen, Aadal, Moe, and Arntzen (2019) and Aadal, Pallesen, Arntzen, and Moe (2018). Especially in Denmark, disabilities were continuously challenged through functional restorations or adjustments that positively impacted reconstruction of the embodied self among the participants. "Having a go" and "learning new things" are related to *becoming* (Lyons et al., 2002) and support the meaning and importance of professional follow-ups that aim to facilitate change and challenge development by optimizing functions throughout recovery, thus supporting reconstruction of the embodied self and QOL.

Study strengths and limitations

The data material was rich and generated by experienced interviewers. Several interesting themes emerged that are not presented in this article. However, the presented analytic text is the most salient in terms of the content and meaning that emerged through the empirical data from the perspectives of a research team with various experiences and knowledge bases. The research team's close knowledge of the data material strengthens the trustworthiness of this study. Reflexivity was central to the interpretative process, and the collective viewing, systematic analysis process and discussions among the authors challenged assumptions across an interdisciplinary research team (3 PTs, 2 OTs, 1 nurse and 1 MD). The findings in this study can be viewed as the best understanding that we have been able to develop and not a statement of the ultimate reality.

To assure that the aim of the study was emphasized, a semi-structured interview guide was collectively developed and used. Further, the interviewers encouraged the informants to talk about their experiences and perspectives by posing open questions. The participants were challenged to lead the conversation, encouraging the interview process to remain as close to the lived experience as possible. Since this study is part of a larger study, the interviewers and participants had previously met through earlier interviews. These established relationships may be a strength of the study by encouraging safety, trust and openness in the conversations. A few conversations involved participants' close family members or others contributing to the study, which may have affected the dynamic between the involved participants and how life or recovery was portrayed. However, in our experience, their contributions were kept to a minimum, and their statements usually elaborated or clarified the meaning of the participants' commentary.

A potential limitation may be that the group of participants included young stroke survivors. Reasonably, certain elements of important aspects for QOL would be different for younger individuals compared to a more average-aged group of stroke survivors. Nevertheless, the findings of this study elaborate on themes that may be helpful for clinicians working with younger stroke survivors. Stroke survivors constitute a heterogenous group, implying that interviews with other participants may have provided other perspectives regarding our research questions, as well as other possible perspectives within and between the two country regions. However, the abstraction process during the analysis supports the findings in this study as significant beyond the individual context.

Conclusion

This study demonstrates different aspects of the embodied self and variations of reconstructing the embodied self one year following stroke. Although the recovery processes and contexts were different, the self-reconstruction process emerged as important for QOL in both countries. We identified three intertwined and negotiating processes: a familiar self, an unfamiliar self, and a recovery of self. Reconstruction of the embodied self was interconnected to bodily changes and functions. Enriching social relations, resumption of activities, successful return to work, and continuity and presence in professional support during the recovery process positively influenced QOL. The described fatigue and reported sustained reduced function, influenced the perceived QOL negatively. The variances in professional support revealed differences in continuity and sustained support between the Central Denmark Region and North Norway and how such differences affected reconstruction of the embodied self.

Clinical implications

In a profound manner, QOL is related to the existential embodied self; how we see ourselves and our possibilities for meaningful interaction with our surroundings. Reconstruction of the embodied self is a means of understanding stroke survivors in the recovery process and has clinical value throughout the various stages of stroke rehabilitation. The intertwined and different aspects of the embodied self inherent to the individual stroke survivor are useful for supporting the evolving self towards a known and familiar self following stroke. Professionals may support the *being, doing* and *becoming* aspects of reconstruction of the embodied self by optimizing restoration of functions, facilitating the development of coping strategies and supporting adjustments in everyday life. Further, professionals can facilitate the *belonging* aspect, e.g., by establishing groups of peers and striving for return to social activities that are important to the individual. The findings indicate the value of continuity in services to support reconstruction of embodied self and QOL among stroke survivors. The complexity and individuality in reconstructing the embodied self are relevant for a personalized and tailored practice aiming towards important and meaningful aspects and activities for the individual—consequently improving their experience of QOL.

Acknowledgments

The authors acknowledge the participants for generously sharing their experiences and time and the health-care professionals for contributing to the recruitment process.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The authors disclose the following financial support for the research, authorship, and publication of this article: The Northern Norway Regional Health Authorities funded this work (grant no. SFP1174-14); Helse Nord RHF.

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PAPER III

Synne Garder Pedersen, Oddgeir Friborg, Guri Anita Heiberg, Cathrine Arntzen, Henriette Holm Stabel, Gyrd Thrane, Jørgen Feldbæk Nielsen, Audny Anke. ***Stroke Specific Quality of Life one-year post-stroke in two Scandinavian country-regions with different organization of rehabilitation services. A prospective study.*** In review 10/2019

Stroke-specific quality of life one-year post-stroke in two Scandinavian country-regions with different organisation of rehabilitation services: A prospective study

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Word count: 4527

Manuscript Title: Stroke-specific quality of life one-year post-stroke in two Scandinavian country-regions with different organisation of rehabilitation services: A prospective study

Running head: Stroke-specific quality of life

Article category: Research paper

Abstract

Purpose: To compare stroke-specific health related quality of life in two country-regions with organisational differences in subacute rehabilitation services, and to reveal whether organisational factors or individual factors impact outcome.

Materials and Methods: A prospective multicentre study with one-year follow-up of 369 first-ever stroke survivors with ischaemic or haemorrhagic stroke, recruited from stroke units in North Norway (n=208) and Central Denmark (n=161). The 12-domain Stroke-Specific Quality of Life scale was the primary outcome-measure.

Results: The Norwegian participants were older than the Danish (M_{age}= 69.8 vs 66.7 years, respectively), had higher initial stroke severity, and longer stroke unit stays. Both cohorts reported more problems with cognitive, social, and emotional functioning compared to physical functioning. Two scale components were revealed. Between-country differences in the cognitive-social-mental component showed slightly better function in the Norwegian participants. Depression, anxiety, pre-stroke dependency, initial stroke severity, and older age were substantially associated to scale scores.

Conclusions: Successful improvements in one-year functioning in both country-regions may result from optimising long-term rehabilitation services to address cognitive, emotional, and social functioning. Stroke-specific quality of life one-year post-stroke could be explained by individual factors, such as pre-stroke dependency and mental health, rather than differences in the organisation of subacute rehabilitation services.

Keywords

stroke, health-related quality of life (HRQOL), Stroke-Specific Quality of Life (SS-QOL) scale, rehabilitation services, countries

Introduction

Stroke is a common cause of disability [1], which may affect functioning in any aspect of a persons' life [2,3]. Multiple functional impairments following stroke may occur separately or combined, including motor functioning, cognition, perception, visual functioning, emotional and mental health, and language problems [4,5]. These functional problems may persist for a considerable amount of time, with long-term effects being determined by the initial stroke lesion and the extent of subsequent recovery [5]. Since the prevalence of stroke-related burden is expected to increase over the next decades, rehabilitation will remain a major part of post-stroke care [6,7]. The rehabilitation process includes aspects of professional care as well as active change, where individuals acquire the necessary knowledge and skills needed for optimum physical, psychological, and social function [5]. To reduce long-term functional consequences and optimise treatment and rehabilitation outcomes, an effective and coordinated organisation with continuum of care is recommended [6,8,9].

The long-term impact of stroke is often investigated by self-reported health-related quality of life (HRQOL) measures, which may be assessed generically if comparisons between diseases are of prime interest, or specifically for the actual disease if distinct clinical aspects of functioning are more important. Thus, the latter represents a more comprehensive assessment of functional domains that are relevant following stroke [10-12]. The most comprehensive stroke-specific HRQOL instruments [11], measure the perceived impact of stroke in several aspects of physical function, activities, and participation [12,13], as defined by the International Classification of Functioning, Disability and Health [14]. These self-report measures are often obtained from, and completed by, stroke survivors with mild to moderate strokes [15-17], and cover physically related domains including mobility and self-care activities, as well as social and psychological domains, including work, language/communication, and cognition [11]. The Stroke-Specific Quality of Life (SS-QOL) scale [18] additionally covers domains related to fatigue, personality change, and vision. Domains rated as most affected vary across studies, with, for example, cognitive-related functions rated as both lower [17] or higher [15] than physical-related functions. Females [19,20], older individuals [20-22], married patients [23], patients who were self-care dependent before the stroke [24,25], and patients with more stroke severity [10,26] have been found to have lower HRQOL. Further, significant correlations between HRQOL levels and psychological factors have been established [10,21,27,28].

Whereas acute phase multidisciplinary stroke unit treatment is evidence-based [29,30], and described as excellent in high-income western countries [31], more knowledge of service provision and rehabilitation effects in the subacute phase is needed [6,32]. For patients with mild to moderate consequences after stroke, evidence suggests skilled, coordinated multidisciplinary teams supporting home-based rehabilitation to increase functioning and regain independence in activities of daily living [6,32,33]. Although continuum of care and access to multidisciplinary rehabilitation in rehabilitation units and after discharge to the community is recommended [6,8,9], it remains unclear how to organise subacute stroke services with optimal delivery [34,35]. Comparing high-income health care systems' methods of organising clinical pathways after stroke and HRQOL, may indicate how to improve rehabilitation services [31,35]. Two European studies have investigated generic HRQOL post-stroke in different countries, and found that HRQOL scores vary more than can be explained by stroke severity or sociodemographic factors alone [24,36]. For example, Ayis et al., [36] observed that significant variations in the physical and mental components of the Short Form Health Survey (SF-12) persisted one year following stroke after adjustments for stroke severity and age. Another study [24] performed additional adjustments with admission to an acute stroke unit, stroke rehabilitation unit, and specific professional support during rehabilitation, but the six-month HRQOL (SF-36) rankings did not change. How countries organise subacute rehabilitation services aimed at alleviating functional problems is likely to influence patients’ HRQOL; hence, studies that examine this are needed [24,36].

We have not found any studies comparing stroke-specific HRQOL between country-regions that differ on overall rehabilitation service organisation following stroke unit treatment. We explored whether stroke survivors from the Danish region with centralised services, standardised and stratified treatment recommendations, and available multidisciplinary stroke-competent community-based teams [37-39], would report higher scores in the stroke-specific HRQOL domains compared to participants from the North Norwegian rural region. Accordingly, the aims of this comparative cohort study were to 1) describe and compare levels and profiles of the SS-QOL scale between cohorts from specified municipalities in two neighbouring countries with different organisation in subacute rehabilitation services one-year post-stroke, 2) explore whether country-region was associated with SS-QOL scores after accounting for selected covariates, and 3) to examine whether the demographic, stroke-related, or psychological factors were associated with SS-QOL scores.

Materials and methods

Setting

This was a prospective international multicentre study with participants living in the geographic area of the University Hospital of North Norway and two municipalities in Central Denmark associated to the University Hospital of Aarhus. The Norwegian area is 23 times larger than the Danish area and include 30 municipalities. In Denmark the study population was admitted to the University Hospital of Aarhus serving 1.3 million inhabitants, whereas the North Norway participants were admitted to one of three stroke units with evident lower patient-volumes. The regions in this study were situated in high-income countries with fairly equivalent public welfare and tax financed healthcare systems, well-organised stroke unit acute rehabilitative treatment, similar high admittance rates to stroke units (>90%), and comparable surveillance-rates post-stroke [40,41]. All citizens had access to specialised acute and stroke unit care with multidisciplinary treatment. The two study regions contrast distinctly in degree of treatment centralisation in stroke units as well as national recommendations of rehabilitation services organisation following stroke unit care. Rehabilitation plans at discharge from stroke units differ, and skilled, specialised multidisciplinary teams are used in the Denmark municipalities, but not in North Norway. Table 1 presents an overview of the geographic and organisational differences in rehabilitation services.

[Table 1 near here]

Participants

Persons with first-time stroke admitted to stroke units and included in the country's respective Stroke Registry, were consecutively enrolled between March 2014 (Norway), or June 2014 (Denmark) through December 2015. Stroke survivors were included if they were 1) 18 years or older; 2) diagnosed with a first-time stroke according to the International Classification of Diseases, version 10 (ICD-10 I.61 or I.63); 3) admitted to the stroke unit of Aarhus University Hospital (Denmark), or one of three stroke units at the University Hospital of North Norway, located at either Tromsø, Harstad or Narvik; and 4) living in either Favrskov or Randers municipality in Denmark, or in the defined geographic area of North Norway. For the current study, stroke survivors had to be able to complete the questionnaires at follow-up. The exclusion criteria were patients with stroke related to brain malignancy, subarachnoid haemorrhage, or brain trauma.

In total, 920 patients with first-time ischaemic or haemorrhage stroke (ICD10 I.63 and I.61) were potential participants for the study (Denmark N=402 and Norway N=518). Of those, 293 persons were excluded at 12 months follow-up (deceased n=174; too sick to be included n=22; consent by proxy, unable to complete the questionnaires n=97). Of the eligible 627 stroke survivors one-year post-stroke, 73 did not consent, 175 did not respond, and 10 were excluded because of unsatisfying completion of the SS-QOL scale. A total of 369 participants were included in the study. A flowchart following the STROBE criteria is shown in figure 1.

Comparing the 73 Norwegian non-consenters with the participants showed that the non-consenters were older ($M_{\text{age}} = 73.6$, $SD_{\text{age}} = 13.5$ vs $M_{\text{age}} = 69.8$, $SD_{\text{age}} = 11.3$), and significantly more were women (63% vs. 43%). Compared with participants, non-responders in both countries had significantly more severe acute stroke assessed with the Scandinavian Stroke Scale, (Norway: $M = 47$, $SD = 8.6$ vs $M = 44$, $SD = 10.4$; Denmark: $M = 49$, $SD = 9.9$ vs $M = 45$, $SD = 14.1$). In addition, the Norwegian non-responders had longer length-of-stay in stroke units than Norwegian participants (median 7 days vs. 4 days). No significant differences in age or gender were found between non-responders and participants in both countries.

[Figure 1 near here]

Data collection procedures and instruments

In the preparation phase of the study, relevant and comparable variables were identified in the national stroke registries of both countries. In Norway, stroke unit nurses or health professionals informed potential participants about the study and asked for written consent either in person or by telephone. In Denmark, a health professional retrieved information directly from the National Stroke Registry on patients with stroke who were living in the respective municipalities. Potential participants were contacted by telephone at three months post-stroke. Those who agreed to answer to interview-questions on rehabilitation and/or complete the questionnaires were enrolled in the study. All potential participants from both regions received a posted questionnaire package one-year post-stroke.

Three months post-stroke, information about rehabilitation services was obtained by telephone or in connection with an outpatient visit. Collected information was based on registrations in the National Norwegian Stroke Registry, and adjusted for use in Denmark for this study. Rehabilitation interventions were registered as: 1) inpatient rehabilitation in a neurorehabilitation unit with a specialised multidisciplinary team; 2) inpatient rehabilitation in a centre with a less specialised multidisciplinary team (not used in Denmark); 3) day centre rehabilitation (municipal); 4) home-based rehabilitation, non-specialised; 5) home-based rehabilitation with an occupational and/or physio- therapist; 6) rehabilitation with a private physical therapist; 7) rehabilitation in a nursing home (not defined in Denmark); 8) other defined interventions; and 9) no rehabilitation after discharge from the stroke unit. The first rehabilitation received after stroke unit admittance was operationalised into: 1) inpatient rehabilitation, either in a specialised neurorehabilitation unit or less specialised rehabilitation unit; 2) community-based rehabilitation at day centres or at home, or; 3) no rehabilitation services after stroke unit discharge.

Demographic data and stroke characteristics

At baseline, data on age, gender, stroke subtype, acute treatment, and length-of-stay were obtained from both countries’ National Stroke Registries. Information on marital status (married/cohabitant or single), pre-stroke self-care dependence (living with or without assistance pre-stroke), and work status (working/studying prior to stroke) were obtained from questionnaires.

The Danish Stroke Registry used the *Scandinavian Stroke Scale* to measure initial stroke severity, and the Norwegian Stroke Registry used the *National Institute of Health Stroke Scale*. Neurologic impairments were measured within 24 hours and were graded in both scales, thus we chose to use the Scandinavian Stroke Scale, because data from the Danish National Stroke Registry was more complete (1 missing) than the National Norwegian Stroke Registry (104 missing for this study). For the Norwegian population missing National Institute of Health Stroke Scale data, a classification was identified by an experienced senior physician (author, G.H) using medical records data. National Institute of Health Stroke Scale scores were transformed to Scandinavian Stroke Scale scores using a mathematical algorithm with a reasonable to good degree of reliability [42].

The Hospital Anxiety and Depression Scale (HADS)

The HADS consists of 14 items, and can be used to reliably and validly detect the mental health states of anxiety (7 items) and depression (7 items) [43], and can be used for persons with stroke [44]. The response scale ranges from 0-3, where higher scores indicate higher severity, and subscale sum scores range from 0-21.

The SS-QOL scale

The outcome measure used to assess the perceived impact of stroke was the comprehensive SS-QOL scale [18,45]. The SS-QOL scale was previously used in Denmark [17] and recently validated for use in the Norwegian language [46]. The scale was developed through interviews with stroke survivors and their closest family members. The SS-QOL scale consists of 49 items covering 12 domains: mobility, energy, upper extremity function, work and productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality. Each domain is measured by three to six items using a 5-point (1-5) Likert scale where higher scores indicate better function. An example from the language domain is “Did you have trouble finding the word you wanted to say?”, and possible replies: 1) couldn´t do it at all, 2) a lot of trouble, 3) some trouble, 4) a little trouble, 5) no trouble at all. A previous study identified two components of the SS-QOL scale, physical and psychosocial, in a study of patients with aneurysmal subarachnoid haemorrhage [47].

Index scores were generated that allowed a comparison of the relative level of each domain and total score. Reliability for the SS-QOL scale has been documented by several studies, with acceptable and good internal consistency of the domains (Cronbach’s alpha= .79-.93 for Norway, and .81-.94 for Denmark). Test-retest reliability of the SS-QOL scale has similarly been documented as generally good (Spearman’s rho=.67-.94 for Norway, and 0.65-0.99 for Denmark) [17,46].

Data quality

Data quality in the completed questionnaires was good. Missing data were collected from participants by telephone when possible. Missing HADS items were replaced by mean subscale scores. Missing SS-QOL items were replaced by the mean scores for the corresponding domain. One or two missing items were accepted for domains with a total of five or six items, and one missing item was allowed for domains with a total of three items. We choose to exclude questionnaires that had more than five missing items in the total scale (2%), and those where we could not generate subscale scores. About 46% of the rehabilitation data were missing for the Danish participants that could not be reached by telephone.

Statistical analyses

Analyses were conducted using IBM SPSS Statistics, version 26. The descriptive data were presented as means, standard deviations (*SD*s), ranges or proportions. Chi-square, or Fisher's Exact tests were used to compare categorical data, whereas independent sample t-tests, or the non-parametric Mann-Whitney U tests, were used to compare differences in continuous data. Binominal distribution (McNemar's test) was used to detect significant dichotomous changes within each country-region. Because of high inter-correlations between the SS-QOL domain scores, we performed a principal component analysis to see if they clustered and formed more general components. The factor loadings were promax rotated (Kappa=4).

Hierarchical linear regression analyses were conducted to identify associations in the SS-QOL scale with the between country-region of prime interest. Variables were entered in blocks, with model fit reported as adjusted R^2 for each block. Four blocks of variables were specified: 1) country, 2) adjustment for age (continuous), gender (male/female), marital status (married/cohabitant vs. single), self-care independent vs. dependent prior to stroke, 3) acute stroke severity, stroke subtype, and length-of-stay in the stroke unit, and 4) HADS anxiety and HADS depression scores. Initial beta values represent each variables' first appearance in the model, whereas final beta values represent the final model. Since the distributional properties of the SS-QOL outcome scores were highly leptokurtic and skewed, the independent T-tests as well as the regression models were bootstrapped with 5,000 re-samplings to produce less biased confidence intervals. Since bootstrapping does not provide standardised beta coefficients, all variables were transformed to z-scores (M=0, SD=1).

Ethics

This study was conducted according to the Helsinki Declaration regarding informed consent and confidentiality. The Danish Data Protection Agency (record no. 1-16-02-363-14) and the Norwegian Committee for Medical Research Ethics (no. 2013/1461) approved the study.

Results

Descriptive data for the two samples is shown in table 2. Most participants had mild (70%) to moderate (26%) initial stroke severity. Participants from North Norway were slightly older than participants from Central Denmark (M_{Norway} = 69.8 years, range 38-91; M_{Denmark} = 66.7 years, range 36-93, $p < .05$), had higher initial stroke severity ($p < .01$), and longer stroke unit length-of-stay (mean 4 vs. 2 days, respectively; $p < .001$). Anxiety and depression levels were not significantly different between the respective cohorts. More participants from Norway were widowed or single before the stroke incidence, and more participants from Denmark were working prior to their stroke.

Rehabilitation pathway data after discharge from the stroke unit were available for all Norwegian participants and for 87 (54%) of the Danish participants. Non-responders at three months follow-up by telephone in Denmark (n=74) did not differ significantly from the Danish participants on age, gender or stroke severity. As shown in table 2, available information indicated more use of inpatient rehabilitation in North Norway, whereas Central Denmark participants received municipality-based rehabilitation services to a higher degree either at home or in a day centre. In the total population, 39% did not have any rehabilitation after discharge from the stroke unit. Significantly fewer Norway participants received rehabilitation after stroke unit discharge compared to Danish participants. Because a large portion of the Danish cohort had missing data for these measures, we choose to present the results only descriptively.

Comparing pre- and post-stroke data, the within country analyses demonstrated a significant decrease in self-care independence (from 93% to 80% in Denmark, and from 89% to 80% in Norway, both *p*'s $< .001$) and work status (from 35% to 22% in Denmark, $p < .001$; from 20% to 14% in Norway, $p < .01$).

[table 2 near here]

A principal component analysis of the 12 sub-domains of the SS-QOL scale extracted two components representing more general dimensions: 1) a physical health component (PH) with strong loadings ranging between .89 and .93 (self-care, mobility, work/productivity, upper extremity function); and 2) a cognitive-social-mental component (CSM) with strong loadings ranging between .82 and .92 (thinking, personality, family roles, mood, social roles, energy). The vision and language domains were excluded because they did not correlate with either of these two components.

The total SS-QOL score was high in both regions ($M_{\text{Norway}} = 4.36$, $SD = .68$; $M_{\text{Denmark}} = 4.19$, $SD = .76$). Participants in both country-regions reported significantly more functional problems in the energy, thinking, mood, personality, social, and family roles domains (table 3, figure 2) compared to the physical domains. A statistically significant difference between the country-regions emerged for five SS-QOL domains; however, these differences were of minor magnitude, with the North Norwegian region showing slightly better function (Cohen's $d_{\text{Energy}} = .26$, $d_{\text{Family roles}} = .28$, $d_{\text{Language}} = .25$, $d_{\text{Thinking}} = .39$ and $d_{\text{Personality}} = .37$). The SS-QOL total scale (Cohen's $d = .24$) and the cognitive-social-mental component ($d = .29$) also showed a small but significant difference.

[Table 3 and Figure 2 near here]

The multiple regression analysis maintained statistical significance for the country difference variable (table 4). Adding the covariates age, pre-stroke dependency, stroke severity, anxiety, and depression explained a substantial amount of the variance in the SS-QOL total score and two component scores (adjusted R^2 ranging between .40 and .59) with anxiety and, in particular, depression being the most substantial explanatory variables followed by pre-stroke self-care dependence and initial stroke severity. For the explained variance in the physical health component of the SS-QOL, HADS anxiety was unimportant, and age (older) contributed slightly. In the cognitive-social-mental component of SS-QOL, age lost significance and stroke severity contributed with a lower magnitude. Replicating these analyses within each country showed the same significant explanatory findings in the Norwegian sample, whereas in the Danish sample age dropped out and gender came in as significant contributors (Supplementary Table S1). There were small changes between initial and final beta values in all regression models.

[Table 4 near here]

Discussion

In this study of multidimensional stroke-specific quality of life across country-regions, individual factors were found to impact outcome more than the organisational differences in subacute rehabilitation services. Both the Norwegian and Danish cohort experienced more problems within cognitive, social, energy, and emotional domains than in physical domains. A principal component analysis of the 12 SS-QOL domains extracted two components that we named the physical health component and the cognitive-social-mental component. Compared to the participants in the North Norwegian region, participants in the Danish region reported more functional problems in the SS-QOL total scale and in the two component scales after adjustment for predefined covariates; thus, this finding did not confirm our expectation of better self-reported HRQOL in the Central Denmark region with more structured subacute multidisciplinary community-based rehabilitation services. Age, self-care dependence, stroke severity, anxiety, and depression were associated with SS-QOL scores.

Domains and profiles of the SS-QOL scale

Compared to other studies [25,48], both regions scored high on the SS-QOL total scale, indicating that the populations with mild to moderate stroke severity had good functioning one-year post-stroke. The SS-QOL scale includes items across body functions, activities, and participation, as classified in the ICF [12]. Previous studies using multidimensional instruments showed variability in scores regarding the domains related to physical and cognitive functions. In contrast to our study, a Turkish study [25] found personality and thinking to be among the domains with highest scores. Also, a Swedish prospective observational study recruiting stroke survivors from stroke units [15], measured HRQOL with the Stroke Impact Scale one-year post-stroke and found that the participants reported more problems with functioning in the physical domains than in the cognitive and social domains. About 87% of the sample for that study were people with initial mild to moderate strokes, and slightly more responders had severe strokes than in our study (13% vs 4%). However, other European studies where the majority of participants had mild and moderate strokes support our findings, reporting relatively more problems in the SS-QOL cognitive, social, and emotional domains [17,47]. Differences and similarities in HRQOL scores may rely on the heterogeneity of the patient populations evaluated, as well as various recruitment procedures for both stroke units and for the different studies. In our study, both cohorts scored lowest in the energy domain one-year post-stroke. Fatigue is common after stroke, tends to persist, and contributes to lower QOL [49,50]. The SS-QOL is the only stroke-specific multidimensional instrument that includes this element to measure stroke-specific HRQOL, which might give the measure an advantage.

Components of comprehensive HRQOL measures

As in our study, a previous validation study of the SS-QOL scale for patients with aneurysmal subarachnoid haemorrhage [47], used principal component analysis and revealed two similar components of the instrument. However, ours is the first study to report two components of the SS-QOL scale in stroke survivors with ischaemic and haemorrhagic stroke. As discussed by others [47], using the two SS-QOL components may be useful for providing scores for physical health and the cognitive-social-mental aspects of the HRQOL without hiding important findings in the total score. Additionally, with the nature of heterogenicity in stroke survivors, the component scores may better indicate specific rehabilitation needs or interventions in different populations or at an individual level.

Country-region differences

The finding that Norwegian participants had higher scores in some of the SS-QOL domains and total scores compared to the Danish participants could be a result of selection bias. The Danish participants were younger, more work-active prior to stroke, and more participants from Denmark were married. However, work-activity and marital status were not significantly associated with the SS-QOL scores, and younger age in this and other studies was predictive for better rather than worse HRQOL scores [20-22]. Rehabilitation services organisation may impact service quality, and thereby outcome, for treated patients [35,51];

therefore, we expected healthier functioning in the Danish than the Norwegian population because of a better organised continuum of care and multidisciplinary professional support in the included Denmark municipalities [37]. The investigated geographic Denmark region has, over the past decade, systematically developed competence in cognitive rehabilitation [37,52], and the Danish population in this study received more municipality-based rehabilitation services after stroke unit discharge compared to the Norwegian cohort. These conditions may matter, given stroke survivors' insight into their own functional dilemmas regarding cognition, consequently resulting in more reported problems. As discussed by others [53,54], people with different expectations may report that they have a different health-related quality of life even when they have the same clinical condition, and current measures cannot distinguish between the individual experience of disease and expectations of health. In contrast, the apparent provision of more inpatient rehabilitation in the North Norwegian region could have a positive impact of functional cognitive abilities [55]. As in previous studies comparing HRQOL across European countries [24,36], variations in SS-QOL scores in our study could not be entirely explained by sociodemographic factors, stroke severity, mental health, or even between country differences in rehabilitation organisation.

Factors associated with the SS-QOL scale

In accordance with most other studies, higher age, pre-stroke dependence, stroke severity, anxiety, and depression were associated with more reported functional problems [10]. Findings regarding age are not fully consistent. While our study demonstrated that higher age was associated with lower SS-QOL total score and physical component scores, age was not of importance for scores in the SS-QOL cognitive-social-mental component. In one study [56], younger stroke survivors (<65 years) reported more problems in social, emotional, vitality, and mental health domains of the SF-36 one-year post-stroke, as well as more problems in the physical health components of SF-36 at three years post-stroke. Another study [57] found no significant difference in SS-QOL scores between stroke survivors above and below 65 years following stroke. As discussed by others [56], associations of HRQOL may vary over time after stroke, and may depend on whether different aspects or components of the multidimensional HRQOL are being considered.

Following a stroke, the occurrence of anxiety and depression is highly clinically significant, and frequently associated with HRQOL [58,59]. Anxiety has been shown to be common following stroke (23-29%), and to have a negative effect on stroke survivors' SS-QOL scores independent from depression [27]. This is consistent with our findings for the SS-QOL total scale and cognitive-social-mental component, whereas anxiety was not a significant explanatory variable for the physical health component. Post-stroke depression is a consistent determinant of HRQOL and probably the most important long-term psychosocial consequence following stroke [10]. Depression after stroke has been reported with a frequency of 18-61% depending on patient selection criteria, diagnostic criteria for depression, and duration after the stroke event [57].

Study strengths and limitations

This study has several limitations. First, selection bias could limit generalisation of results. Although the inclusion criteria were identical, the study samples differed between the country-regions. Norwegian participants were slightly older and had higher initial stroke severity than Danish participants. A possible explanation could be different stroke unit admission practices. Although controlling for this type of difference is never fully possible, we expected regression analyses to account for case mix [36]. Next, factorial invariance (e.g., whether the given measure is interpreted in a conceptually similar manner by respondents representing different cultural backgrounds) is a prerequisite for generalising results from patient reported outcome measures. To the best of our knowledge, the SS-QOL scale has not previously been compared across cultures and an evaluation of measurement quality related to this study has not been done, representing a limitation of our study. Although the two countries included in this study have quite similar cultures and languages, a cultural difference in interpretation of the questionnaire cannot be ruled out. Third, given the extensive questionnaire used, results cannot be generalised to patients with severe disabilities or aphasia following stroke. Nevertheless, results are consistent with studies on stroke survivors with mild to moderate stroke. Finally, missing data for rehabilitation pathways after the stroke unit were an additional study limitation. However, the available data supported the descriptive comparison of rehabilitation organisation between the two country-regions. In the future, when ongoing work is completed, a more standardised classification of rehabilitation services will be available [60,61]. Study strengths include recruitment from stroke units in countries with high admittance rates, definition of geographic areas, few exclusion criteria, and standardised measurements.

Acknowledgements

This work was supported by the Northern Norway Regional Health Authorities (grant no. SFP1174-14); Helse Nord RHF.

Declaration of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and publication of this article.

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Figure captions

Figure 1: Flowchart.

Figure 2: Stroke-Specific Quality of Life scoring profiles in Norway and Denmark.

Table 1. Geographic and organisational differences in acute and subacute stroke rehabilitation in the study regions (2014-2016)

	Rehabilitation services in the Central Denmark region study area	**Rehabilitation services in the region of North-Norway study area**
Location	Central Region, Denmark	Northern Region, Norway
Study area	Area: 1,288 kvm^2 Inhabitants: 146,536 Municipalities: Two Inhabitants per municipality: 48,000 and 97,000	Area: 30,000 kvm^2 Inhabitants: 190,000 Municipalities: Thirty Inhabitants per municipality: 870 – 72,000
Acute and subacute inpatient rehabilitation	One centralised stroke unit covering 1.3 million inhabitants	Three stroke units covering 30,000, 50’000 and 110,000 inhabitants. The largest has Level 1 responsibility for an expanded area.
	Referral from stroke unit possible to: - two highly specialised inpatient neurorehabilitation units	Referral from stroke unit possible to: - two neurorehabilitation units - four less specialised rehabilitation units
	Continuous treatment chain from acute care to rehabilitation	No regularly continuous treatment chain
	Rehabilitation settings with available robot training, virtual reality training, pool / warm pool	No regularly available technical resources/pool
Outpatient and community- based rehabilitation	Multidisciplinary, specialised team available when indicated	Seldom have multidisciplinary teams in municipalities
	Day-rehabilitation at a centre	No available day-rehabilitation at a centre
	Specialised follow-up of stroke consequences (return to work, cognitive problems)	No regularly available multidisciplinary specialised follow-up, but use of ambulatory counselling teams
	Family involvement, if present	No regular family involvement

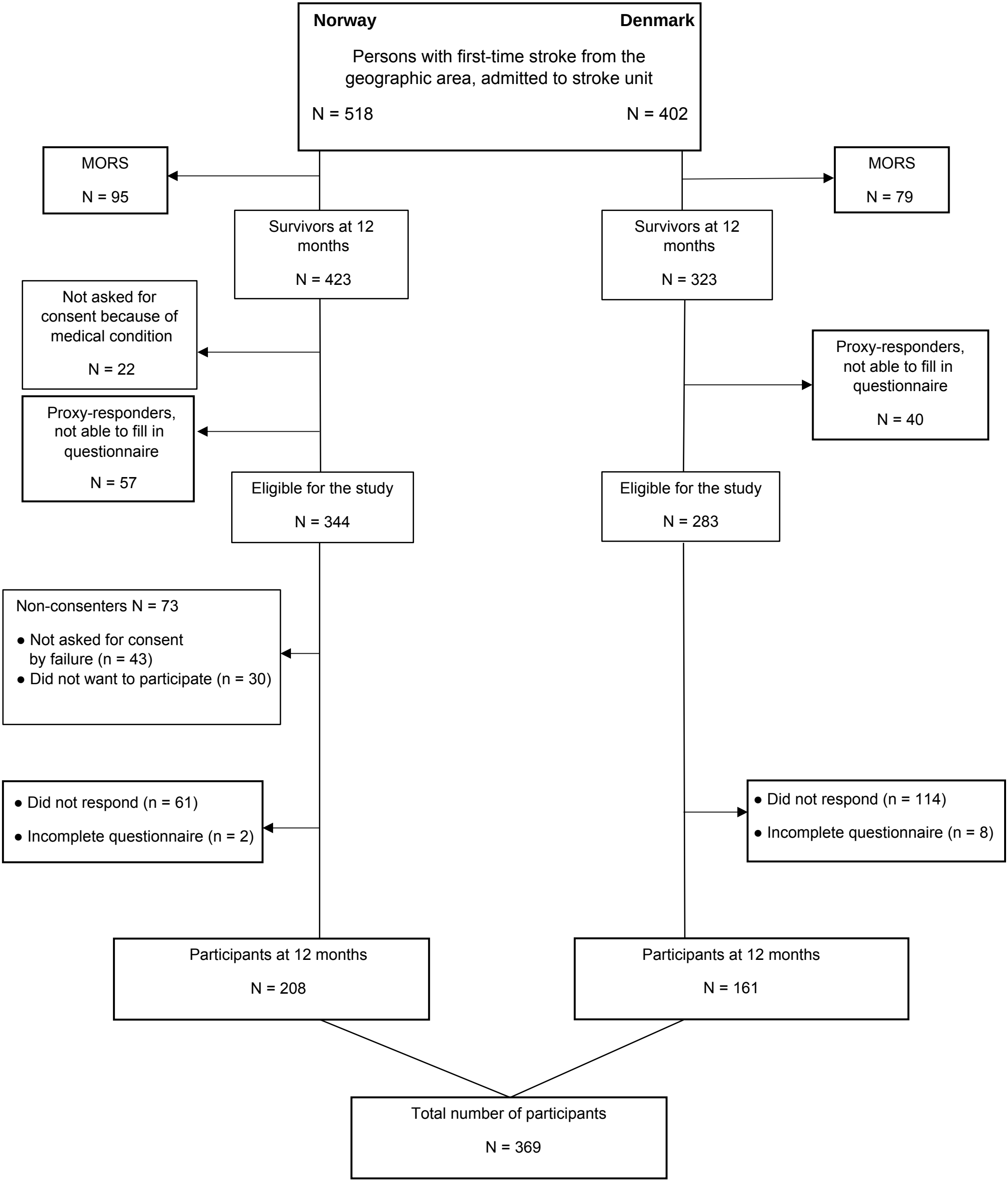

Norway
Denmark
Persons with first-time stroke from the geographic area, admitted to stroke unit
N = 518
N = 402
MORS
N = 95
MORS
N = 79
Survivors at 12 months
N = 423
Survivors at 12 months
N = 323
Not asked for consent because of medical condition
N = 22
Proxy-responders, not able to fill in questionnaire
N = 57
Proxy-responders, not able to fill in questionnaire
N = 40
Eligible for the study
N = 344
Eligible for the study
N = 283
Non-consenters N = 73
● Not asked for consent by failure (n = 43)
● Did not want to participate (n = 30)
● Did not respond (n = 61)
● Incomplete questionnaire (n = 2)
● Did not respond (n = 114)
● Incomplete questionnaire (n = 8)
Participants at 12 months
N = 208
Participants at 12 months
N = 161
Total number of participants
N = 369

Table 2.
Demographic, stroke characteristics and treatment factors of participants with first-time stroke

	Both regions	Norway	Denmark
	N=369	*N*=208	*N*=161
Age at time of injury, mean (*SD*) [a]	68.4 (11.4)	69.8 (11.3)	66.7 (11.4)
Age, n (%)	56 (15)	26 (12)	30 (19)
18-55	199 (54)	108 (52)	91 (56)
56-74	114 (31)	74 (36)	40 (25)
>75			
Gender, n (%)			
Female	153 (42)	88 (43)	65 (40)
Male	216 (58)	120 (57)	96 (60)
Stroke subtype, n (%)			
Ischemic	336 (91)	191 (92)	145 (90)
Haemorrhagic	33 (9)	17 (9)	16 (10)
Married/cohabitant, n (%) [a]	248 (67)	131 (63)	117 (74)
Working or student, n (%) [a]	97 (26)	42 (20)	55 (35)
Living home with assistance/ institution, n (%)	36 (10)	24 (11)	12 (7)
Scandinavian Stroke Scale (SSS), median [IQR] [b]	49 [44-56]	47 [43-54]	52 [44-57]
SSS impairment, n (%)			
45-58 mild	257 (70)	137 (66)	120 (75)
30-44 moderate	96 (26)	63 (30)	33 (20)
0-29 severe and very severe	15 (4)	8 (4)	7 (4)
Missing	-	-	1 (1)
Stroke unit length-of-stay, median [IQR] [c]	3 [2-6]	4 [3-7]	2 [1-3]
Thrombolysis, n (%)	60 (16)	28 (14)	32 (20)
Thrombectomy, n (%) [a]	9 (2)	2 (1)	7 (4)
Available participants, telephone interview at 3 months	*N*=295	*N*=208	*N*=87
Rehabilitation after stroke unit			
In-patient rehabilitation, n (%) [b]	84 (23)	70 (34)	14 (16)
Community-based rehabilitation at home or day-centre, n (%) [c]	69 (19)	29 (14)	40 (46)
No follow-up after stroke unit, n (%) [c]	142 (39)	109 (52)	33 (38)

[a] Cohort difference p=<0.05
[b] Cohort difference p=<0.01
[c] Cohort difference p=<0.001

Table 3. Stroke-Specific Quality of Life scores in Norway and Denmark one-year post-stroke.

	Norway *N* = 208		Denmark *N* = 161		
	M	95% *CI*	*M*	95% *CI*	*p*
Index scores					
Mobility	4.51	4.4 - 4.6	4.54	4.4 - 4.6	.683
Energy	3.73	3.5 - 3.9	3.37	3.1 - 3.6	.017
Upper extremity function	4.53	4.4 - 4.6	4.47	4.3 - 4.6	.528
Work/productivity	4.54	4.4 - 4.7	4.42	4.3 - 4.5	.154
Mood	3.98	3.8 - 4.1	3.78	3.6 - 4.0	.115
Self-care	4.73	4.6 - 4.8	4.70	4.6 - 4.8	.649
Social roles	3.99	3.8 - 4.1	3.77	3.6 - 4.0	.074
Family roles	4.26	4.1 - 4.4	3.94	3.7 - 4.1	.009
Vision	4.78	4.7 - 4.8	4.70	4.6 - 4.8	.194
Language	4.72	4.6 - 4.8	4.57	4.5 - 4.7	.014
Thinking	4.07	3.9 - 4.2	3.60	3.4 - 3.8	.000
Personality	4.23	4.1 - 4.4	3.79	3.7 - 4.1	.001
Total score	4.36	4.3 - 4.4	4.19	4.1 - 4.3	.024
Component scores					
physical health (PH) [1]	4.58	4.5 – 4.7	4.55	4.5 – 4.6	.673
cognitive-social-mental (CSM) [2]	4.03	3.9 – 4.2	3.72	3.5 – 3.9	.008

Notes. *M* = mean, 95% *CI* = bootstrapped confidence interval.

[1]= self-care, vision, language, mobility, work/productivity, upper extremity function

[2]= thinking, personality, family role, mood, social role, energy

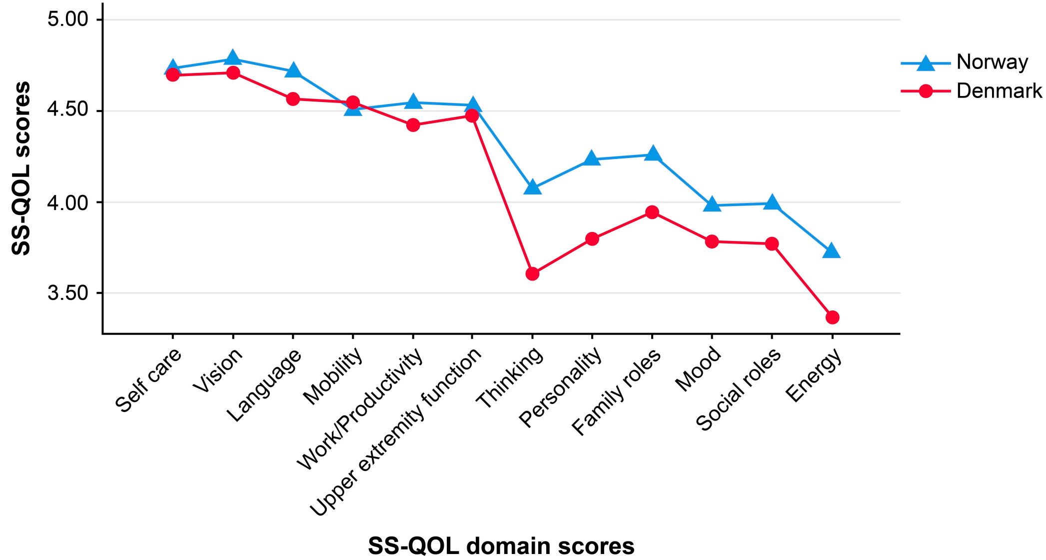

SS-QOL scores
5.00
4.50
4.00
3.50
Norway
Denmark
Self care
Vision
Language
Mobility
Work/Productivity
Upper extremity function
Thinking
Personality
Family roles
Mood
Social roles
Energy
SS-QOL domain scores

Table 4. Regression analysis of the Stroke-Specific Quality of Life (SS-QOL) total scale and the two component scales. Independent variables were entered in four blocks.

Block **Covariates**	**SS-QOL total**			**SS-QOL physical health (PH) component**			**SS-QOL cognitive-social-mental (CSM) component**		
	Adj R^2	Initial β	Final β 95% CI	Adj R^2	Initial β	Final β 95% CI	Adj R^2	Initial β	Final β 95% CI
1 Country difference	.01	-.129^{a}	-.164^{c} -.238 I -.093	-.00	-.037	-.121^{b} -.206 I -.043	.02	-.151^{b}	-151^{c} -.226 I -.080
2 Background information	.08			.11			.06		
Age		.027	-.095^{a} -.184 I -.008		-.125	-.171^{b} -.301 I -.059		.127	-.016 -.105 I .070
Gender		-.056	.054 -.014 I .124		-.034	.009 -.077 I .096		-.061	.066 -.009 I .142
Marital status		.010	.007 -.068 I .085		.046	.045 -.042 I .142		-.005	-.005 -.078 I .072
Work status		.057	-.016 -.095 I .061		-.044	-.011 -.099 I .070		-.071	-.034 -.112 I .045
Dependency		-.270^{c}	-.183^{b} -.313 I -.070		-.292^{c}	-.225^{b} -.388 I -.081		-.213^{b}	-.131^{a} -.231 I -.039
3 Stroke and length-of-stay	.17			.23			.10		
Stroke severity (SSS)*		.277^{c}	.184^{c} .101 I .265		.282^{c}	.213^{b} .078 I .335		.207^{c}	.117^{b} .042 I .194
Stroke subtype		-.023	.026 -.034 I .084		-.039	-.009 -.090 I .077		-.020	.032 -.029 I .092
Length-of-stay, stroke unit (days)		-.066	-.020 -.159 I .085		-.152	-.125 -.322 I -.002		-.014	.033 -.073 I .123
4 Questionnaire data (one-year)	.59			.40			.56		
HADS anxiety#			-.253^{c} -.351 I -.158			-.037 -.173 I .086			-.333^{c} -.438 I -.234
HADS depression#			-.478^{c} -.584 I -.370			-.390^{c} -.532 I -.258			-.447^{c} -.563 I -.340

Notes. Country: Norway=1, Denmark=2. Gender: 1 ♂, 2 ♀, Marital status: married/cohabitant=1, single/widowed=2.
Work status: student/working=1, sick-leave/retired=2, Dependency: Independent=1, dependent=2

* Higher score, better function, # Higher score, worse function
SSS = Scandinavian Stroke Scale, HADS = Hospital Anxiety and Depression Scale

Physical health (PH) component: self-care, mobility, work/productivity, upper extremity function
Cognitive-social-mental (CSM) component: thinking, personality, family role, mood, social role, energy
${}^{a}\rho < .05$, ${}^{b}\rho < .01$, ${}^{c}\rho < .001$

Supplementary Table S1.

Regression analysis for the Stroke-Specific Quality of Life (SS-QOL) scale for both regions and for each region in Norway and Denmark

Block **Covariates**	**SS-QOL both regions**			**SS-QOL Norway**			**SS-QOL Denmark**		
	Adj R^2	Initial β	Final β 95% CI	Adj R^2	Initial β	Final β 95% CI	Adj R^2	Initial β	Final β 95% CI
1 Country difference	.01								
		-.129^{a}	-.164^{c} -.238 I -.093						
2 Background information	.08			.11			.04		
Age		.027	-.095^{a} -.184 I -.008		-.097	-.139^{a} -.263 I -.013		.172	-.048 -.169 I .066
Gender		-.056	.054 -.014 I .124		-.096	.010 -.085 I .107		.002	.105^{b} .004 I .204
Marital status		.010	.007 -.068 I .085		.044	.018 -.083 I .125		-.025	.021 -.078 I .141
Work status		.057	-.016 -.095 I .061		.009	.021 -.092 I .134		-.129	-.046 -.153 I .057
Dependency		-.270^{c}	-.183^{b} -.313 I -.070		-.256^{b}	-.183^{a} -.362 I -.039		-.257^{b}	-.183^{a} -.347 I -.010
3 Stroke and length-of-stay	.17			.19			.15		
Stroke severity (SSS)		.277^{c}	.184^{c} .101 I .265		.225^{a}	.160^{a} .015 I .289		.345^{b}	.208^{b} .096 I .319
Stroke subtype		-.023	.026 -.034 I .084		-.104^{a}	-.015 -.100 I .072		.099	.076 -.017 I .166
Length-of-stay, stroke unit (days)		-.066	-.020 -.159 I .085		-.158	-.093 -.273 I .060		.032	.041 -.139 I .301
4 Questionnaire data (one-year)	.59			.52			.64		
HADS anxiety			-.253^{c} -.351 I -.158			-.194^{b} -.326 I -.082			-.322^{b} -.497 I -.155
HADS depression			-.478^{c} -.584 I -.370			-.456^{b} -.578 I -.322			-.466^{b} -.672 I -.279

Notes. Country: Norway=1, Denmark=2. Gender: 1 ♂, 2 ♀, Marital status: married/cohabitant=1, single/widowed=2.
Work status: student/working=1, sick-leave/retired=2, Dependency: Independent=1, dependent =2

SSS = Scandinavian Stroke Scale, HADS = Hospital Anxiety and Depression Scale
$^{a}\rho < .05$, $^{b}\rho < .01$, $^{c}\rho < .001$

Appendices 1 – 10

1. Decision Regional Committee for Health Research Ethics – main study
2. Decision Regional Committee for Health Research Ethics
3. Information and consent form – paper I and III
4. Questionnaire package – three months – paper I
5. Questionnaire package – 12 months – paper I and paper III
6. Acute phase data from the National Norwegian Stroke Registry
7. Follow-up registrations at three months from the National Norwegian Stroke Registry
8. Follow-up registrations adjusted for use in Denmark at three months
9. Information and consent – paper II
10. Interview guide

Appendix 1

Decision Regional Committee for Health Research Ethics – main study

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			05.03.2014	2013/1472/REK nord
			Deres dato:	**Deres referanse:**
			08.10.2013	

Vår referanse må oppgis ved alle henvendelser

Audny Anke
Rehabiliteringsklinikken, UNN HF

2013/1472 Rehabiliteringsforløp, funksjon og livskvalitet etter hjerneslag i Nord-Norge og Danmark

Forskningsansvarlig: Universitetssykehuset Nord Norge
Prosjektleder: Audny Anke.

Prosjektleders prosjektomtale
Sammenlignende populasjonsbaserte studier etter hjerneslag gir relativt like funn av letalitet, mens det i mindre grad finnes sammenlignende studier av funksjon, livskvalitet og rehabiliteringstiltak etter slagenhet. I Nord-Norge gis rehabilitering på små enheter med lite pasientvolum, mens Danmark har høyere grad av sentralisering. Begge land bruker slagenheter og trombolyse. Norge-Norge har spesielle geografiske utfordringer. Studien er en prospektiv sammenlignende internasjonal multisenterstudie av slagpasienter fra UNN Tromsø/Harstad/Narvik og Århus i Danmark, i samarbeid med Hammel Neurocenter. Basis-informasjon hentes fra hjerneslagregistrene i begge land. Datainnsamling ved 3 og 12 måneder vil gi informasjon om funksjonell status (Modified Rankin Scale), hjelpebehov, bosted, livskvalitet (SSQOL-DK, QOLIBRI, EQ-5D, HADS) og behandlingstilfredshet i de to kohorter. Behandlingskjeden kartlegges med vekt på rehabiliteringstiltak.

Bakgrunn
Prosjektsøknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møte den 26.9.2013. Komiteen hadde merknader til søknaden og fattet utsettelsesvedtak hvor den videre behandling av søknaden vil bli foretatt av en samlet komité.

Prosjektleder har gjennom møte med sekretariatet, samt ved skriftlige tilbakemeldinger gitt tilfredsstillende tilbakemelding på komiteens merknader. Tilbakemeldingen ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møte 20.02.2014.

Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Vedtak:
Med hjemmel i helseforskningsloven § 10 og forskningsetikkloven § 4 godkjennes prosjektet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest (et halvt år etter prosjektslutt), jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Prosjektleder kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK nord.

Klagefristen er tre uker fra mottak av dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til: kari.holthe@unn.no; rek-svar@unn.no

Appendix 2

Decision Regional Committee for Health Research Ethics

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			05.03.2014	2013/1461/REK nord
			Deres dato:	**Deres referanse:**
			08.10.2013	

Vår referanse må oppgis ved alle henvendelser

Cathrine Arntzen
Breivika, Universitetet i Tromsø

2013/1461 Sammenheng mellom rehabiliteringsforløp og livskvalitet ett år etter hjerneslag i Nord-Norge og Danmark. En mixed method studie

Forskningsansvarlig: Universitetssykehuset Nord Norge
Prosjektleder: Cathrine Arntzen

Prosjektleders prosjektomtale

Helsetjenesten har behov for mer kunnskap om hva kontekstuell variasjon, regionale utfordringer og lokale løsninger betyr for rehabiliteringsforløpet etter hjerneslag. Studien skal beskrive rehabiliteringsforløpet til personer med hjerneslag i Nord-Norge og Danmark og hva det betyr for opplevd livskvalitet. Ved å beskrive og sammenligne forløpsdata fra ulike pasientkohorter i to skandinaviske land vil studien bidra til evaluering av dagens tilbud og gjennom sammenligninger og analyser tilføre en kunnskapsbase til nytte for utviklingen av rehabiliteringsfeltet. En populasjonsbasert prospektiv studie med systematisk registrering av rehabiliteringstilbud og helserelatert livskvalitet gjennomføres i kombinasjon med kvalitativ kontekstuell analyse av rehabiliteringsforløp og livskvalitet basert på pasienterfaringer.

Vi viser til tilbakemelding på komiteens merknader for ovennevnte prosjektsøknad. Tilbakemeldingen ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 20.02.2014.

Bakgrunn

Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møte den 26.9.2013. Komiteen hadde merknader til søknaden og fattet utsettelsesvedtak hvor den videre behandling av søknaden vil bli foretatt av en samlet komité.

Prosjektleder har gjennom møte med sekretariatet, samt ved skriftlige tilbakemeldinger gitt tilfredsstillende tilbakemelding på komiteens merknader.

Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikklovens § 4.

Vedtak:

Med hjemmel i helseforskningsloven § 10 og forskningsetikkloven § 4 godkjennes prosjektet.

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest (et halvt år etter prosjektslutt), jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang

Prosjektleder kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK nord.

Klagefristen er tre uker fra mottak av dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til: kari.holthe@unn.no; rek-svar@unn.no

Appendix 3

Information and consent form – paper I and III

Forespørsel om deltakelse i forskningsprosjektet

"Rehabiliteringsforløp, funksjon og livskvalitet etter hjerneslag i Nord-Norge og Danmark"

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie som sammenligner forløpet for pasienter med hjerneslag i Nord-Norge og i en region i Danmark, hvilke behandlings- og rehabiliteringstiltak som gis og hvordan det går det første året etter hjerneslaget. Studien gjennomføres for å få bedre kunnskap om hvordan det går med pasienter med hjerneslag og hvilke behov de har. Studien er et samarbeid mellom rehabiliteringssenteret Hammel Neurocenter i Danmark og Universitetssykehuset Nord-Norge, og kan bidra til at rehabiliteringstilbudet bedres.

Hva innebærer studien?

I forbindelse med innleggelsen og ved telefonisk kontakt 3 måneder etter hjerneslaget registreres opplysninger som inngår i Norsk Hjerneslagregister. Dette er dato for hjerneslaget, tid fra du merket symptomer til innleggelsen, og resultater fra undersøkelser om årsak til hjerneslaget, behandlingstype, eventuelle komplikasjoner, diagnoser, liggetid, utskrivingssted og hjelpetiltak. Det kartlegges også hvilke problemer du har og hvordan du klarer deg i hverdagen. Som del av studien vil det per telefon bli stilt noen tilleggsspørsmål om rehabiliteringstiltak etter utskriving. Du vil få tilsendt et spørreskjema i posten 3 måneder og 12 måneder etter hjerneslaget. I skjemaet spør vi om bakgrunnsdata som familie, utdanning, arbeidssituasjon og bosted. Det er spørsmål om i hvilken grad du opplever problemer med forskjellige daglige aktiviteter, sosiale sammenhenger, følelsesmessige forhold, og om du opplever endringer i din situasjon etter hjerneslaget. I tillegg er det spørsmål om tilfredshet med ulike livsområder og om hvor tilfreds du er med behandlingen og/eller rehabiliteringen.

Mulige fordeler og ulemper

Studien medfører ingen form for risiko eller ubehag annet enn at du besvarer spørsmål ved telefonkontakt og fyller ut de ulike spørreskjemaene. Studien bidrar til bedre kunnskap om problemer etter et hjerneslag, og resultatene i studien vil bli benyttet til å bedre rehabiliteringstilbudet.

Hva skjer med informasjonen om deg

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Informasjon om hjerneslaget og behandlingen du får hentes fra journal på det sykehus som behandler deg og fra Norsk Hjerneslagregister. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Informasjonen som samles vil bli slettet innen utgangen av år 2020. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Audny Anke, prosjektleder, førsteamanuensis dr.med. Universitetssykehuset Nord-Norge, tlf.95936333; eller Guri Heiberg, overlege, UNN Harstad, tlf.95948500; eller Synne Garder Pedersen, fysioterapeut, UNN Tromsø tlf. 91838630.

Kapittel A- utdypende forklaring av hva studien innebærer

Pasienter innlagt med hjerneslag ved en av de tre slagenhetene ved UNN Tromsø, UNN Harstad eller UNN Narvik blir forespurt om deltakelse. Pasient og pårørende blir informert om studien ved innleggelsen og samtykke innhentet så raskt pasientens tilstand tillater det. Studien innebærer ikke påvirkning av behandling, men dersom problemer i behandlingsapparatet oppdages vil studieleder kontakte behandlingsansvarlig.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er i hovedtrekk hentet fra din journal samt spørreskjemaene om problemer og funksjon som du fyller ut. Mange av de opplysninger som registreres i Norsk Hjerneslagregister inngår i studien. Ved 3 måneder vil du bli spurt om behandling og rehabilitering etter utskriving, og vi innhenter opplysninger fra de sykehus eller rehabiliteringsinstitusjoner om hvor lenge du ligger der og hvilken form for medisinsk behandling og rehabilitering du får. All informasjon om deg avidentifiseres og studiens medarbeidere og forskere får kun tilgang til avidentifisert informasjon.
Universitetssykehuset Nord-Norge ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre

Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til forskere ved Hammel Neurocenter Danmark som deltar i studien.

Rett til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Studien er finansiert gjennom forskningsmidler fra Helse Nord RHF.

Forsikring

Deltakerne i studien er omfattet av Pasientskadeerstatningen.

Informasjon om utfallet av studien

Du har som deltaker rett til å få informasjon om studiens resultater.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

----

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 4

Questionnaire package – three months – paper I

Livet etter hjerneslag

Rehabiliteringsforløp, funksjon og livskvalitet 3 måneder etter hjerneslag.

En studie i Norge og Danmark

Pasientidentifikasjon:

Introduksjon og formål med undersøkelsen

Dette er en spørreundersøkelse for å vurdere funksjon og livskvalitet tre måneder etter hjerneslag. Spørreskjemaet sendes til personer som har gjennomgått hjerneslag i utvalgte kommuner i Nord-Norge og i Midt-Jylland i Danmark.

Svarene i dette spørreskjema gir et overblikk over hvor fornøyd du er med livet ditt og hvor godt du klarer daglige gjøremål tre måneder etter hjerneslaget. Vi ønsker også informasjon om ditt sosiale liv, arbeid, utdannelse, bosituasjon og hvor tilfreds du er med behandlings- og rehabiliteringstilbudet. Alle personlige opplysninger vil bli anonymisert.

Dersom du ***ikke*** selv klarer å besvare spørreskjemaet, ber vi om at en pårørende, en venn eller en fagperson som kjenner deg godt, svarer på spørsmålene på side 2-4. Vi ber også om at den som fyller ut opplyser om hvilken relasjon vedkommende har til deg, og hvor ofte dere møtes. Øvrige spørsmål i spørreskjemaet skal da ***ikke*** besvares. Det tar ca. 3 minutter å besvare disse spørsmålene.

Veiledning

Spørreskjemaet inneholder flere typer spørsmål som skal besvares ulikt. Vennligst les instruksjonen for hvert skjema nøye.

Det kan være spørsmål som ligner hverandre. Det skal du se bort fra, og besvare alle spørsmålene etter beste evne. ***Det er viktig at alle spørsmål besvares.***

Det tar ca. 30 min å fylle ut spørreskjemaet.

Returnering av spørreskjemaet

Du bes om å returnere spørreskjemaet i den vedlagte svarkonvolutten, senest . . . .
Porto er forhåndsbetalt.

Takk for hjelpen!

Dato for utfylling:

Spørsmål om utdanning, arbeid, bolig og sivilstatus

I spørreskjemaet ber vi deg om å sette et kryss for det svaret som passer best for deg. For noen spørsmål gjelder det både for perioden ***før*** hjerneslaget og perioden ***i dag***. Med ***før*** mener vi hvordan situasjonen var ***den dagen du fikk hjerneslag***. For eksempel skal du opplyse om hvilken arbeidssituasjon du var i den dagen du fikk slaget, og ikke ta med opplysninger om tidligere arbeid. Dette gjelder alle spørsmål der vi spør etter ***før*** og ***i dag***.

UTDANNING

- ☐ Mindre enn 7 år
- ☐ 8-10 år (grunnskole)
- ☐ 11-14 år (videregående, yrkesutdanning)
- ☐ Over 14 år (høgskole eller universitetsutdanning)

ARBEID ELLER TRYGDEYTELSER

Før hjerneslaget	I dag	
☐	☐	Student
☐	☐	Hjemmeværende
☐	☐	I full jobb
☐	☐	I deltidsjobb, vennligst oppgi timeantall pr. uke:
☐	☐	Alderspensjonist
☐	☐	Uførepensjonist
☐	☐	Sykemeldt
☐	☐	Arbeidsledig

BOLIG

Før hjerneslaget	I dag	
☐	☐	Egen bolig ***uten*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Egen bolig ***med*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Eldrebolig, omsorgsbolig eller bolig med mulighet for å tilkalle personale
☐	☐	Sykehjem eller institusjon med fast personale

SIVILSTATUS

Før hjerneslaget	I dag	
☐	☐	Gift eller samboer
☐	☐	Enke eller enkemann
☐	☐	Bor alene

RØYKING

Ja	Nei	
☐	☐	Røkte du før du fikk hjerneslag?
☐	☐	Røyker du i dag?
☐	☐	Er du tidligere røyker (røykfri i mer enn 1 måned)?

Vi vil gjerne vite om du synes du har kommet deg helt etter hjerneslaget, og om du får hjelp av andre til daglige gjøremål.

Ja	Nei	
☐	☐	Synes du at du har kommet deg helt etter hjerneslaget?
☐	☐	Får du hjelp av andre til noen av dine daglige gjøremål?

Relasjoner

Dersom spørsmålene ovenfor er besvart ***av en annen enn den som har hatt hjerneslag,*** ber vi om at du opplyser om din relasjon til vedkommende, og hvor hyppig dere møtes. Sett bare ***et*** kryss for hvert spørsmål. Du skal ikke besvare resten av spørsmålene i dette spørreskjemaet. Takk for hjelpen.

RELASJON

☐ Ektefelle eller samboer
☐ Sønn eller datter
☐ Venn
☐ Helsearbeider
☐ Annen relasjon. Angi hvilken:

KONTAKTHYPPIGHET

Hvor ofte treffer du den som har hatt et hjerneslag?

☐ Daglig
☐ Minst 1 gang i uken
☐ Sjeldnere enn 1 gang i uken

Tilfredshet med livet etter hjerneslag

Vi ønsker å vite hvor fornøyd du er med forskjellige deler av livet ditt etter hjerneslaget

Du bes om for hvert spørsmål å sette kryss ved det svaret som passer best til hvordan du har det nå (den siste uken). Sett bare ett kryss for hvert spørsmål.

	Ikke i det hele tatt	Litt fornøyd	Moderat fornøyd	Ganske fornøyd	Meget fornøyd
Alt i alt, hvor fornøyd er du med din fysiske helse?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine evner til å konsentrere deg, huske og tenke?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine følelser og den sinnsstemning du har?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med hvordan du klarer dine daglige gjøremål?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med ditt personlige og sosiale liv?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med din nåværende situasjon og dine framtidsutsikter?	☐	☐	☐	☐	☐

Referanse: von Steinbüechel N. et al. QOLIBRI- OS (2012)

Livskvalitet etter hjerneslag

Dette skjema handler om daglige aktiviteter, erfaringer og om hvordan du har det ***nå*** sammenlignet med ***før*** hjerneslaget. Alle spørsmål gjelder opplevelsene du har hatt den siste uken.

Vanlige daglige aktiviteter

Sett ***ett*** kryss for hvert spørsmål om hvordan du har klart daglige aktiviteter den siste uken.

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
1	Hadde du problemer med å tilberede et måltid?	☐	☐	☐	☐	☐
2	Hadde du problemer med å spise?	☐	☐	☐	☐	☐
3	Hadde du problemer med påkledning?	☐	☐	☐	☐	☐
4	Hadde du problemer med å ta et bad eller en dusj?	☐	☐	☐	☐	☐
5	Hadde du problemer med å gå på toalettet?	☐	☐	☐	☐	☐
6	Hadde du problemer med å se tydelig nok på tv?	☐	☐	☐	☐	☐

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
7	Hadde du problemer med å strekke deg etter ting på grunn av dårlig syn?	☐	☐	☐	☐	☐
8	Hadde du problemer med å se ting på den ene siden av synsfeltet?	☐	☐	☐	☐	☐
9	Hadde du problemer med å snakke?	☐	☐	☐	☐	☐
10	Hadde du problemer med å snakke klart og tydelig i telefon?	☐	☐	☐	☐	☐
11	Hadde andre mennesker problemer med å forstå hva du sa?	☐	☐	☐	☐	☐
12	Hadde du problemer med å finne ord som du ville si?	☐	☐	☐	☐	☐
13	Måtte du gjenta deg selv slik at andre kunne forstå deg?	☐	☐	☐	☐	☐
14	Hadde du problemer med å gå? (Sett kryss i "Kunne overhodet ikke" hvis du ikke kan gå, og fortsett på spørsmål 17.)	☐	☐	☐	☐	☐
15	Hadde du problemer med å holde balansen når du lente deg frem eller strakk deg etter noe?	☐	☐	☐	☐	☐
16	Hadde du problemer med å gå opp trapper?	☐	☐	☐	☐	☐
17	Hadde du behov for å ta pause mens du gikk eller brukte rullestol?	☐	☐	☐	☐	☐
18	Hadde du problemer med å stå?	☐	☐	☐	☐	☐
19	Hadde du problemer med å reise deg fra en stol?	☐	☐	☐	☐	☐
20	Hadde du problemer med å klare de daglige gjøremål i hjemmet?	☐	☐	☐	☐	☐
21	Hadde du problemer med å gjøre ferdig oppgaver du hadde begynt på?	☐	☐	☐	☐	☐
22	Hadde du problemer med å utføre de oppgaver som du pleier?	☐	☐	☐	☐	☐
23	Hadde du problemer med å skrive for hånd eller bruke tastatur?	☐	☐	☐	☐	☐
24	Hadde du problemer med å ta på sokker?	☐	☐	☐	☐	☐
25	Hadde du problemer med å kneppe knapper?	☐	☐	☐	☐	☐
26	Hadde du problemer med å bruke glidelås?	☐	☐	☐	☐	☐
27	Hadde du problemer med å åpne et glass med skrulokk?	☐	☐	☐	☐	☐

Erfaringer den siste uken

Hvert utsagn berører problemer som man kan oppleve etter hjerneslag. Her skal du angi hvorvidt du er enig eller uenig i utsagnene nedenfor. Alle utsagn gjelder den siste uken.

Sett ***ett*** kryss for hvert spørsmål

	Den siste uken:	Helt enig	Delvis enig	Verken enig eller uenig	Delvis uenig	Helt uenig
28	Jeg hadde problemer med å konsentrere meg.	☐	☐	☐	☐	☐
29	Jeg hadde problemer med å huske ting	☐	☐	☐	☐	☐
30	Jeg måtte skrive ned ting for å huske dem	☐	☐	☐	☐	☐
31	Jeg var irritabel	☐	☐	☐	☐	☐
32	Jeg var utålmodig med andre	☐	☐	☐	☐	☐
33	Personligheten min har endret seg	☐	☐	☐	☐	☐
34	Jeg følte meg motløs med tanke på fremtiden	☐	☐	☐	☐	☐
35	Jeg var ikke interessert i andre mennesker eller aktiviteter	☐	☐	☐	☐	☐
36	Jeg deltok mindre i lystbetonte aktiviteter med min familie	☐	☐	☐	☐	☐
37	Jeg følte at jeg var en byrde for min familie	☐	☐	☐	☐	☐
38	Min fysiske tilstand påvirket mitt familieliv	☐	☐	☐	☐	☐
39	Jeg gikk ikke ut så ofte som jeg ønsket	☐	☐	☐	☐	☐
40	Jeg brukte mindre tid på fritidsinteresser enn jeg ville	☐	☐	☐	☐	☐
41	Jeg traff ikke så mange av mine venner som jeg ville	☐	☐	☐	☐	☐
42	Jeg hadde sex mer sjelden enn jeg ønsket	☐	☐	☐	☐	☐
43	Min fysiske tilstand påvirket mitt sosiale liv	☐	☐	☐	☐	☐
44	Jeg følte meg isolert fra andre mennesker	☐	☐	☐	☐	☐
45	Jeg hadde lite selvtillit	☐	☐	☐	☐	☐
46	Jeg hadde liten matlyst	☐	☐	☐	☐	☐
47	Jeg følte meg trøtt mesteparten av tiden	☐	☐	☐	☐	☐
48	Jeg måtte ofte hvile meg i løpet av dagen	☐	☐	☐	☐	☐
49	Jeg var for trøtt til å gjøre det jeg ville	☐	☐	☐	☐	☐

Endringer etter hjerneslaget

Her skal du svare på hvordan du har det nå, sammenlignet med tiden før hjerneslaget.

Sett ***ett*** kryss på det svaret som best beskriver din tilstand nå.

		Betydelig endret	Noe endret	Litt endret	Uendret
50	Min personlighet er	☐	☐	☐	☐

		Mye dårligere enn før	Noe dårligere enn før	Litt dårligere enn før	Uendret
51	Energinivået mitt er	☐	☐	☐	☐
52	Språkevnen min er	☐	☐	☐	☐
53	Gangfunksjonen min er	☐	☐	☐	☐
54	Synet mitt er	☐	☐	☐	☐
55	Armene og hendene mine fungerer	☐	☐	☐	☐
56	Min evne til å tenke er	☐	☐	☐	☐
57	Humøret mitt er	☐	☐	☐	☐
58	Jeg utfører oppgavene mine i hjemmet eller på arbeid	☐	☐	☐	☐
59	Jeg klarer meg selv	☐	☐	☐	☐
60	Jeg gjør noe for familien min	☐	☐	☐	☐
61	Jeg gjør noe for vennene mine	☐	☐	☐	☐
62	Alt i alt er min livskvalitet	☐	☐	☐	☐

Stroke Specific Quality of Life Scale - DK (Muus I. et al. 2005)

Sinnsstemning/følelser

Dette skjemaet undersøker hvordan du har hatt det den siste uken. Sett ***ett*** kryss ved det svaret som best beskriver dine følelser. Ikke tenk for lenge på svaralternativene – de spontane svarene er best.

1. Jeg føler meg nervøs og urolig

- ☐ Mesteparten av tiden
- ☐ Mye av tiden
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

2. Jeg gleder meg fortsatt over tingene slik jeg pleide før

- ☐ Avgjort like mye
- ☐ Ikke fullt så mye
- ☐ Bare lite grann
- ☐ Ikke i det hele tatt

3. Jeg har en urofølelse som om noe forferdelig vil skje

- ☐ Ja, og noe svært ille
- ☐ Ja, ikke så veldig ille
- ☐ Litt, bekymrer meg lite
- ☐ Ikke i det hele tatt

4. Jeg kan le og se det morsomme i situasjoner

- ☐ Like mye nå som før
- ☐ Ikke like mye nå som før
- ☐ Avgjort ikke som før
- ☐ Ikke i det hele tatt

5. Jeg har hodet fullt av bekymringer

- ☐ Veldig ofte
- ☐ Ganske ofte
- ☐ Av og til
- ☐ En gang i blant

6. Jeg er i godt humør

- ☐ Aldri
- ☐ Noen ganger
- ☐ Ganske ofte
- ☐ For det meste

7. Jeg kan sitte i fred og ro og kjenne meg avslappet

- ☐ Ja, helt klart
- ☐ Vanligvis
- ☐ Ikke så ofte
- ☐ Ikke i det hele tatt

8. Jeg føler meg som om alt går langsommere

- ☐ Nesten hele tiden
- ☐ Svært ofte
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

9. Jeg føler meg urolig som om jeg har sommerfugler i magen

- ☐ Ikke i det hele tatt
- ☐ Fra tid til annen
- ☐ Ganske ofte
- ☐ Svært ofte

10. Jeg bryr meg ikke lengre om hvordan jeg ser ut

- ☐ Ja, jeg har sluttet å bry meg
- ☐ Ikke som jeg burde
- ☐ Kan hende ikke nok
- ☐ Bryr meg som før

11. Jeg er rastløs som om jeg stadig må være aktiv

- ☐ Uten tvil svært mye
- ☐ Ganske mye
- ☐ Ikke så veldig mye
- ☐ Ikke i det hele tatt

12. Jeg ser med glede frem til hendelser og ting

- ☐ Like mye som før
- ☐ Heller mindre enn før
- ☐ Avgjort mindre enn før
- ☐ Nesten ikke i det hele tatt

13. Jeg kan plutselig få en følelse av panikk

- ☐ Uten tvil svært ofte
- ☐ Ganske ofte
- ☐ Ikke så veldig ofte
- ☐ Ikke i det hele tatt

14. Jeg kan glede meg over gode bøker, radio og tv

- ☐ Ofte
- ☐ Fra tid til annen
- ☐ Ikke så ofte
- ☐ Svært sjelden

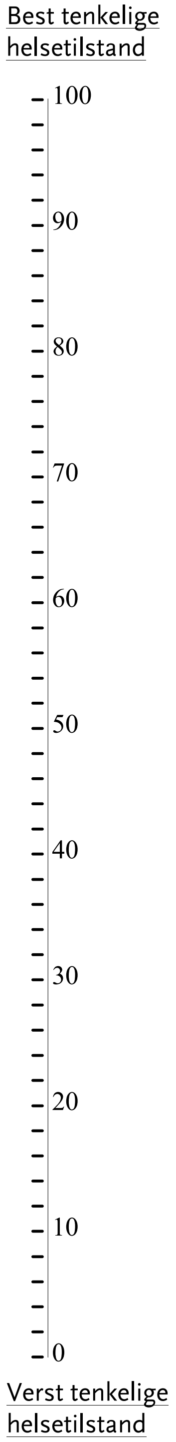
HAD (Zigmond og Snaith 1983)

HELSETILSTAND

På skalaen nedenfor ber vi deg om å markere hvor god eller dårlig din helsetilstand er i dag. Du angir dette, ved å tegne en strek fra boksen til det punkt på skalaen.

Den beste helsetilstanden du kan forestille deg er markert med “100”, og den verst tenkelige helsetilstanden er markert med “0”

Nåværende
helsetilstand



Beskrivelse av helsetilstand

Her finner du fem ulike tema med tre ulike svaralternativer. Sett ***ett*** kryss for det svaralternativet som best beskriver din helsetilstand i dag.

1. Gange

- ☐ Jeg har ingen problemer med å gå omkring
- ☐ Jeg har litt problemer med å gå omkring
- ☐ Jeg er sengeliggende

2. Personlig stell

- ☐ Jeg har ingen problemer med personlig stell
- ☐ Jeg har litt problemer med å vaske meg eller kle på meg
- ☐ Jeg er ute av stand til å vaske meg eller kle på meg

3. Vanlige gjøremål

- ☐ Jeg har ingen problemer med å utføre mine vanlige gjøremål
- ☐ Jeg har litt problemer med å utføre mine vanlige gjøremål
- ☐ Jeg er ute av stand til å utføre mine vanlige gjøremål

4. Smerte og ubehag

- ☐ Jeg har verken smerte eller ubehag
- ☐ Jeg har moderate smerter eller ubehag
- ☐ Jeg har sterke smerter eller ubehag

5. Angst og depresjon

- ☐ Jeg er verken engstelig eller deprimert
- ☐ Jeg er noe engstelig eller deprimert
- ☐ Jeg er svært engstelig eller deprimert

EQ 5D the EuroQol Group 1990

Tilfredshet med behandling og rehabilitering

I dette skjemaet skal du svare på hvor tilfreds du er med behandlingen, treningen og rehabiliteringstilbudet som du har fått i forbindelse med hjerneslaget.

Sett ***ett*** kryss for hvert av de tre spørsmålene.

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *under innleggelse* på sykehuset?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd
☐ Jeg fikk ikke trening eller rehabilitering under innleggelse

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *etter utskrivelse* fra sykehuset?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd
☐ Jeg fikk ikke trening eller rehabilitering etter utskrivelse

Hvor tilfreds er du med samarbeidet mellom sykehus og kommune i forbindelse med utskrivelse fra sykehuset?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd

Alt i alt, hvor fornøyd er du med behandlingen og rehabiliteringen etter hjerneslaget?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd

Hjelp til utfylling

Ja	Nei	
☐	☐	Har du fått hjelp til utfylling av spørreskjemaet

Takk for hjelpen!

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Appendix 5

Questionnaire package – 12 months – paper I and paper III

Livet etter hjerneslag

Rehabiliteringsforløp, funksjon og livskvalitet 12 måneder etter hjerneslag.

En studie i Norge og Danmark

Pasientidentifikasjon:

Introduksjon og formål med undersøkelsen

Dette er en spørreundersøkelse for å vurdere funksjon og livskvalitet tolv måneder etter hjerneslag. Spørreskjemaet sendes til personer som har gjennomgått hjerneslag i utvalgte kommuner i Nord-Norge og i Midt-Jylland i Danmark.

Svarene i dette spørreskjema gir et overblikk over hvor fornøyd du er med livet ditt og hvor godt du klarer daglige gjøremål tolv måneder etter hjerneslaget. Vi ønsker også informasjon om ditt sosiale liv, arbeid, utdannelse, bosituasjon og hvor tilfreds du er med behandlings- og rehabiliteringstilbudet. Alle personlige opplysninger vil bli anonymisert.

Dersom du ***ikke*** selv klarer å besvare spørreskjemaet, ber vi om at en pårørende, en venn eller en fagperson som kjenner deg godt, svarer på spørsmålene på side 3-4. Vi ber også om at den som fyller ut opplyser om hvilken relasjon vedkommende har til deg, og hvor ofte dere møtes. Øvrige spørsmål i spørreskjemaet skal da ***ikke*** besvares. Det tar ca. 3 minutter å besvare disse spørsmålene.

Veiledning

Spørreskjemaet inneholder flere typer spørsmål som skal besvares ulikt. Vennligst les instruksjonen for hvert skjema nøye.

Det kan være spørsmål som ligner hverandre. Det skal du se bort fra, og besvare alle spørsmålene etter beste evne. ***Det er viktig at alle spørsmål besvares.***

Det tar ca. 30 min å fylle ut spørreskjemaet.

Returnering av spørreskjemaet

Du bes om å returnere spørreskjemaet i den vedlagte svarkonvolutten, senest . . . .
Porto er forhåndsbetalt.

Takk for hjelpen!

Dato for utfylling:

Spørsmål om utdanning, arbeid, bolig og sivilstatus

I spørreskjemaet ber vi deg om å sette et kryss for det svaret som passer best for deg. For noen spørsmål gjelder det både for perioden ***før*** hjerneslaget og perioden ***i dag***. Med ***før*** mener vi hvordan situasjonen var ***dagen før du fikk hjerneslag***. For eksempel skal du opplyse om hvilken arbeidssituasjon du var i dagen før du fikk slaget, og ikke ta med opplysninger om tidligere arbeid. Dette gjelder alle spørsmål der vi spør etter ***før*** og ***i dag***.

ARBEID ELLER TRYGDEYTELSER

Før hjerneslaget	I dag	
☐	☐	Student
☐	☐	Hjemmeværende
☐	☐	I full jobb
☐	☐	I deltidsjobb, vennligst oppgi timeantall pr. uke:
☐	☐	Alderspensjonist
☐	☐	Uførepensjonist
☐	☐	Sykemeldt
☐	☐	Arbeidsledig

BOLIG (Angi hvilken type bolig du bodde i før hjerneslaget, og hvilken type bolig du bor i nå)

Før hjerneslaget	I dag	
☐	☐	Egen bolig ***uten*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Egen bolig ***med*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Eldrebolig, omsorgsbolig eller bolig med mulighet for å tilkalle personale
☐	☐	Sykehjem eller institusjon med fast personale

SIVILSTATUS

Før hjerneslaget	I dag	
☐	☐	Gift eller samboer
☐	☐	Enke eller enkemann
☐	☐	Bor alene

RØYKING

Ja	Nei	
☐	☐	Røkte du før du fikk hjerneslag?
☐	☐	Røyker du i dag?
☐	☐	Er du tidligere røyker (røykfri i mer enn 1 måned)?

Vi vil gjerne vite om du synes du har kommet deg helt etter hjerneslaget, og om du får hjelp av andre til daglige gjøremål.

Ja	Nei	
☐	☐	Synes du at du har kommet deg helt etter hjerneslaget?
☐	☐	Får du hjelp av andre til noen av dine daglige gjøremål?

Aktuelle problemer etter et hjerneslag

I tabellen nedenfor ber vi om at du angir i hvor stor grad du har problemer og redusert funksjon etter hjerneslaget. Tabellen kan fylles ut av pasient, pårørende eller helsepersonell:

Sett én ring rundt det tallet som best beskriver din situasjon ***i dag***.

STATUS ETTER HJERNESLAG	
0	***Ingen symptomer i det hele tatt***
1	***Ingen betydningsfull/synlig funksjonssvikt*** Lette symptomer, men ingen problemer i det daglige, og klarer å utføre alle vanlige aktiviteter som før.
2	***Lett funksjonssvikt*** Klarer ikke å utføre alle aktiviteter som før, men klarer de fleste daglig gjøremål. Klarer seg selv uten hjelp.
3	***Moderat funksjonssvikt*** Trenger noe hjelp til daglige gjøremål. Kan gå uten hjelp.
4	***Alvorlig funksjonssvikt*** Trenger mye hjelp til personlig hygiene, toalettbesøk, og andre daglige gjøremål. Kan ikke gå uten hjelp.
5	***Svært alvorlig funksjonssvikt*** Trenger konstant tilsyn og hjelp. Er sengeliggende og avhengig av at det er der noen der nesten hele tiden.
6	***Ukjent***

Referanse: Modified Rankin Scale. Rankin 1957

Relasjoner

Dersom spørsmålene ovenfor er besvart ***av en annen enn den som har hatt hjerneslag,*** ber vi om at du opplyser om din relasjon til vedkommende, og hvor hyppig dere møtes. Sett bare ***et*** kryss for hvert spørsmål. Du skal ikke besvare resten av spørsmålene i dette spørreskjemaet. Takk for hjelpen.

RELASJON

- ☐ Ektefelle eller samboer
- ☐ Sønn eller datter
- ☐ Venn
- ☐ Helsearbeider
- ☐ Annen relasjon. Angi hvilken:

KONTAKTHYPPIGHET

Hvor ofte treffer du den som har hatt et hjerneslag?

- ☐ Daglig
- ☐ Minst 1 gang i uken
- ☐ Sjeldnere enn 1 gang i uken

Tilfredshet med livet etter hjerneslag

Vi ønsker å vite hvor fornøyd du er med forskjellige deler av livet ditt etter hjerneslaget

Du bes om for hvert spørsmål å sette kryss ved det svaret som passer best til hvordan du har det nå (den siste uken). Sett bare ett kryss for hvert spørsmål.

	Ikke i det hele tatt	Litt fornøyd	Moderat fornøyd	Ganske fornøyd	Meget fornøyd
Alt i alt, hvor fornøyd er du med din fysiske helse?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine evner til å konsentrere deg, huske og tenke?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine følelser og den sinnsstemning du har?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med hvordan du klarer dine daglige gjøremål?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med ditt personlige og sosiale liv?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med din nåværende situasjon og dine framtidsutsikter?	☐	☐	☐	☐	☐

Referanse: von Steinbüechel N. et al. QOLIBRI- OS (2012)

Livskvalitet etter hjerneslag

Dette skjema handler om daglige aktiviteter, erfaringer og om hvordan du har det ***nå*** sammenlignet med ***før*** hjerneslaget. Alle spørsmål gjelder opplevelsene du har hatt den siste uken.

Vanlige daglige aktiviteter

Sett ***ett*** kryss for hvert spørsmål om hvordan du har klart daglige aktiviteter den siste uken.

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
1	Hadde du problemer med å tilberede et måltid?	☐	☐	☐	☐	☐
2	Hadde du problemer med å spise?	☐	☐	☐	☐	☐
3	Hadde du problemer med påkledning?	☐	☐	☐	☐	☐
4	Hadde du problemer med å ta et bad eller en dusj?	☐	☐	☐	☐	☐
5	Hadde du problemer med å gå på toalettet?	☐	☐	☐	☐	☐
6	Hadde du problemer med å se tydelig nok på tv?	☐	☐	☐	☐	☐

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
7	Hadde du problemer med å strekke deg etter ting på grunn av dårlig syn?	☐	☐	☐	☐	☐
8	Hadde du problemer med å se ting på den ene siden av synsfeltet?	☐	☐	☐	☐	☐
9	Hadde du problemer med å snakke?	☐	☐	☐	☐	☐
10	Hadde du problemer med å snakke klart og tydelig i telefon?	☐	☐	☐	☐	☐
11	Hadde andre mennesker problemer med å forstå hva du sa?	☐	☐	☐	☐	☐
12	Hadde du problemer med å finne ord som du ville si?	☐	☐	☐	☐	☐
13	Måtte du gjenta deg selv slik at andre kunne forstå deg?	☐	☐	☐	☐	☐
14	Hadde du problemer med å gå? (Sett kryss i "Kunne overhodet ikke" hvis du ikke kan gå, og fortsett på spørsmål 17.)	☐	☐	☐	☐	☐
15	Hadde du problemer med å holde balansen når du lente deg frem eller strakk deg etter noe?	☐	☐	☐	☐	☐
16	Hadde du problemer med å gå opp trapper?	☐	☐	☐	☐	☐
17	Hadde du behov for å ta pause mens du gikk eller brukte rullestol?	☐	☐	☐	☐	☐
18	Hadde du problemer med å stå?	☐	☐	☐	☐	☐
19	Hadde du problemer med å reise deg fra en stol?	☐	☐	☐	☐	☐
20	Hadde du problemer med å klare de daglige gjøremål i hjemmet?	☐	☐	☐	☐	☐
21	Hadde du problemer med å gjøre ferdig oppgaver du hadde begynt på?	☐	☐	☐	☐	☐
22	Hadde du problemer med å utføre de oppgaver som du pleier?	☐	☐	☐	☐	☐
23	Hadde du problemer med å skrive for hånd eller bruke tastatur?	☐	☐	☐	☐	☐
24	Hadde du problemer med å ta på sokker?	☐	☐	☐	☐	☐
25	Hadde du problemer med å kneppe knapper?	☐	☐	☐	☐	☐
26	Hadde du problemer med å bruke glidelås?	☐	☐	☐	☐	☐
27	Hadde du problemer med å åpne et glass med skrulokk?	☐	☐	☐	☐	☐

Erfaringer den siste uken

Hvert utsagn berører problemer som man kan oppleve etter hjerneslag. Her skal du angi hvorvidt du er enig eller uenig i utsagnene nedenfor. Alle utsagn gjelder den siste uken.

Sett ***ett*** kryss for hvert spørsmål

	Den siste uken:	Helt enig	Delvis enig	Verken enig eller uenig	Delvis uenig	Helt uenig
28	Jeg hadde problemer med å konsentrere meg.	☐	☐	☐	☐	☐
29	Jeg hadde problemer med å huske ting	☐	☐	☐	☐	☐
30	Jeg måtte skrive ned ting for å huske dem	☐	☐	☐	☐	☐
31	Jeg var irritabel	☐	☐	☐	☐	☐
32	Jeg var utålmodig med andre	☐	☐	☐	☐	☐
33	Personligheten min har endret seg	☐	☐	☐	☐	☐
34	Jeg følte meg motløs med tanke på fremtiden	☐	☐	☐	☐	☐
35	Jeg var ikke interessert i andre mennesker eller aktiviteter	☐	☐	☐	☐	☐
36	Jeg deltok mindre i lystbetonte aktiviteter med min familie	☐	☐	☐	☐	☐
37	Jeg følte at jeg var en byrde for min familie	☐	☐	☐	☐	☐
38	Min fysiske tilstand påvirket mitt familieliv	☐	☐	☐	☐	☐
39	Jeg gikk ikke ut så ofte som jeg ønsket	☐	☐	☐	☐	☐
40	Jeg brukte mindre tid på fritidsinteresser enn jeg ville	☐	☐	☐	☐	☐
41	Jeg traff ikke så mange av mine venner som jeg ville	☐	☐	☐	☐	☐
42	Jeg hadde sex mer sjelden enn jeg ønsket	☐	☐	☐	☐	☐
43	Min fysiske tilstand påvirket mitt sosiale liv	☐	☐	☐	☐	☐
44	Jeg følte meg isolert fra andre mennesker	☐	☐	☐	☐	☐
45	Jeg hadde lite selvtillit	☐	☐	☐	☐	☐
46	Jeg hadde liten matlyst	☐	☐	☐	☐	☐
47	Jeg følte meg trøtt mesteparten av tiden	☐	☐	☐	☐	☐
48	Jeg måtte ofte hvile meg i løpet av dagen	☐	☐	☐	☐	☐
49	Jeg var for trøtt til å gjøre det jeg ville	☐	☐	☐	☐	☐

Endringer etter hjerneslaget

Her skal du svare på hvordan du har det nå, sammenlignet med tiden før hjerneslaget.

Sett ***ett*** kryss på det svaret som best beskriver din tilstand nå.

		Betydelig endret	Noe endret	Litt endret	Uendret
50	Min personlighet er	☐	☐	☐	☐

		Mye dårligere enn før	Noe dårligere enn før	Litt dårligere enn før	Uendret
51	Energinivået mitt er	☐	☐	☐	☐
52	Språkevnen min er	☐	☐	☐	☐
53	Gangfunksjonen min er	☐	☐	☐	☐
54	Synet mitt er	☐	☐	☐	☐
55	Armene og hendene mine fungerer	☐	☐	☐	☐
56	Min evne til å tenke er	☐	☐	☐	☐
57	Humøret mitt er	☐	☐	☐	☐
58	Jeg utfører oppgavene mine i hjemmet eller på arbeid	☐	☐	☐	☐
59	Jeg klarer meg selv	☐	☐	☐	☐
60	Jeg gjør noe for familien min	☐	☐	☐	☐
61	Jeg gjør noe for vennene mine	☐	☐	☐	☐
62	Alt i alt er min livskvalitet	☐	☐	☐	☐

Stroke Specific Quality of Life Scale (Williams et al. 1999)

Sinnsstemning/følelser

Dette skjemaet undersøker hvordan du har hatt det den siste uken. Sett ***ett*** kryss ved det svaret som best beskriver dine følelser. Ikke tenk for lenge på svaralternativene – de spontane svarene er best.

1. Jeg føler meg nervøs og urolig

- ☐ Mesteparten av tiden
- ☐ Mye av tiden
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

2. Jeg gleder meg fortsatt over tingene slik jeg pleide før

- ☐ Avgjort like mye
- ☐ Ikke fullt så mye
- ☐ Bare lite grann
- ☐ Ikke i det hele tatt

3. Jeg har en uroføelse som om noe forferdelig vil skje

☐ Ja, og noe svært ille
☐ Ja, ikke så veldig ille
☐ Litt, bekymrer meg lite
☐ Ikke i det hele tatt

4. Jeg kan le og se det morsomme i situasjoner

☐ Like mye nå som før
☐ Ikke like mye nå som før
☐ Avgjort ikke som før
☐ Ikke i det hele tatt

5. Jeg har hodet fullt av bekymringer

☐ Veldig ofte
☐ Ganske ofte
☐ Av og til
☐ En gang i blant

6. Jeg er i godt humør

☐ Aldri
☐ Noen ganger
☐ Ganske ofte
☐ For det meste

7. Jeg kan sitte i fred og ro og kjenne meg avslappet

☐ Ja, helt klart
☐ Vanligvis
☐ Ikke så ofte
☐ Ikke i det hele tatt

8. Jeg føler meg som om alt går langsommere

☐ Nesten hele tiden
☐ Svært ofte
☐ Fra tid til annen
☐ Ikke i det hele tatt

9. Jeg føler meg urolig som om jeg har sommerfugler i magen

☐ Ikke i det hele tatt
☐ Fra tid til annen
☐ Ganske ofte
☐ Svært ofte

10. Jeg bryr meg ikke lengre om hvordan jeg ser ut

☐ Ja, jeg har sluttet å bry meg
☐ Ikke som jeg burde
☐ Kan hende ikke nok
☐ Bryr meg som før

11. Jeg er rastløs som om jeg stadig må være aktiv

☐ Uten tvil svært mye
☐ Ganske mye
☐ Ikke så veldig mye
☐ Ikke i det hele tatt

12. Jeg ser med glede frem til hendelser og ting

☐ Like mye som før
☐ Heller mindre enn før
☐ Avgjort mindre enn før
☐ Nesten ikke i det hele tatt

13. Jeg kan plutselig få en følelse av panikk

☐ Uten tvil svært ofte
☐ Ganske ofte
☐ Ikke så veldig ofte
☐ Ikke i det hele tatt

14. Jeg kan glede meg over gode bøker, radio og tv

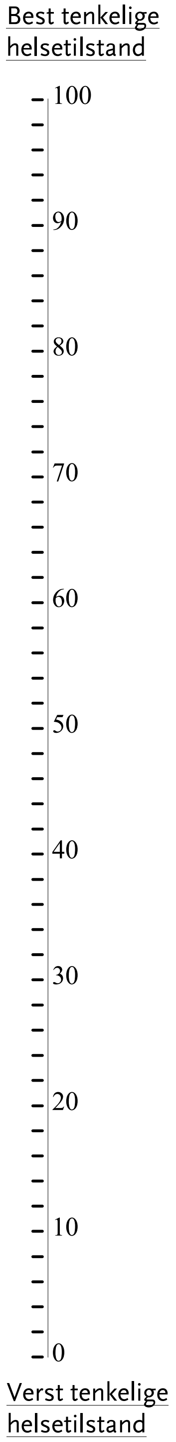
☐ Ofte
☐ Fra tid til annen
☐ Ikke så ofte
☐ Svært sjelden

HAD (Zigmond og Snaith 1983)

HELSETILSTAND

På skalaen nedenfor ber vi deg om å markere hvor god eller dårlig din helsetilstand er i dag. Du angir dette, ved å tegne en strek fra boksen til det punkt på skalaen.

Den beste helsetilstanden du kan forestille deg er markert med “100”, og den verst tenkelige helsetilstanden er markert med “0”



Nåværende helsetilstand

Beskrivelse av helsetilstand

Her finner du fem ulike tema med tre ulike svar-alternativer. Sett ***ett*** kryss for det svaralternativet som best beskriver din helsetilstand i dag.

1. Gange

- ☐ Jeg har ingen problemer med å gå omkring
- ☐ Jeg har litt problemer med å gå omkring
- ☐ Jeg er sengeliggende

2. Personlig stell

- ☐ Jeg har ingen problemer med personlig stell
- ☐ Jeg har litt problemer med å vaske meg eller kle på meg
- ☐ Jeg er ute av stand til å vaske meg eller kle på meg

3. Vanlige gjøremål

- ☐ Jeg har ingen problemer med å utføre mine vanlige gjøremål
- ☐ Jeg har litt problemer med å utføre mine vanlige gjøremål
- ☐ Jeg er ute av stand til å utføre mine vanlige gjøremål

4. Smerte og ubehag

- ☐ Jeg har verken smerte eller ubehag
- ☐ Jeg har moderate smerter eller ubehag
- ☐ Jeg har sterke smerter eller ubehag

5. Angst og depresjon

- ☐ Jeg er verken engstelig eller deprimert
- ☐ Jeg er noe engstelig eller deprimert
- ☐ Jeg er svært engstelig eller deprimert

EQ 5D the EuroQol Group 1990

Tilfredshet med behandling og rehabilitering

I dette skjemaet skal du svare på hvor tilfreds du er med behandlingen, treningen og rehabiliteringstilbudet som du har fått i forbindelse med hjerneslaget.

Sett ***ett*** kryss for hvert av de tre spørsmålene.

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *under innleggelse* på sykehuset?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd
☐ Jeg fikk ikke trening eller rehabilitering under innleggelse

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *etter utskrivelse* fra sykehuset?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd
☐ Jeg fikk ikke trening eller rehabilitering etter utskrivelse

Alt i alt, hvor fornøyd er du med behandlingen og rehabiliteringen etter hjerneslaget?

☐ Meget fornøyd
☐ Fornøyd
☐ Verken fornøyd eller misfornøyd
☐ Misfornøyd
☐ Meget misfornøyd

Har du blitt mottatt trening eller rehabilitering i perioden fra 3 måneder etter hjerneslaget?

☐ Ja
☐ Nei

Hvis ja, mottar du trening eller rehabilitering nå?

☐ Ja
☐ Nei

Hjelp til utfylling

Ja	Nei	
☐	☐	Har du fått hjelp til utfylling av spørreskjemaet

Takk for hjelpen!

Tromsprodukt · 40 00 72 02

Appendix 6

Acute phase data from the National Norwegian Stroke Registry

Norsk hjerneslagregister

Akuttskjema 2015

Anvendes ved registrering av alle pasienter innlagt med akutt hjerneslag fra og med 01.01.2015

Personnummer ☐☐☐☐☐☐☐☐☐☐☐

Navn ☐

Adresse ☐

Telefon ☐

Inklusjonskontroll. Pasienten har hjerneslagdiagnose i henhold til ett av følgende kriterier:

☐ 1 Akutte fokale utfall + positiv bildediagnostikk. Innlagt i sykehus innen 28 døgn fra symptomdebut.

☐ 2 Akutte fokale utfall ÷ positiv bildediagnostikk. Innlagt i sykehus innen 28 døgn fra symptomdebut.

☐ 3 Ingen av ovennevte, pasienten skal ikke registreres

Slagdiagnose

☐ I 61 Hjerneblødning (CT/MR eller obduksjon har vist blødning)

☐ I 63 Hjerneinfarkt (CT/MR obduksjon er uten aktuell patologi eller har vist et aktuelt infarkt)

☐ I 64 Hjerneslag ikke spesifisert som blødning eller infarkt (CT/MR ikke tatt)

☐ Hjerneslag som hoveddiagnose

☐ Hjerneslag som bidiagnose

For pasienter med primær hjerneblødning:

Er det gitt blødningsstoppende behandling?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, hvilken?

☐ 1 Faktorkonsentrat (Octaplex)

☐ 2 Ferskt frosset plasma (Octaplas)

☐ 3 K-vitamin

☐ 4 Faktorkonsentrat + 2 eller 3

☐ 5 Annet

Tilstand før det aktuelle hjerneslaget

Boligforhold

☐ 1 Egen bolig uten hjemmesykepleie/hjemmehjelp

☐ 2 Egen bolig med hjemmesykepleie/hjemmehjelp

☐ 3 Omsorgsbolig med døgnkontinuerlige tjenester og personale

☐ 4 Sykehjem

☐ 9 Ukjent

Sivilstatus

☐ 1 Gift/samboende

☐ 2 Enke/enkemann

☐ 3 Enslig

☐ 9 Ukjent

Bosituasjon

☐ 1 Pasienten bodde alene

☐ 2 Pasienten bodde sammen med noen (f.eks. ektefelle/samboer, søsken, barn)

☐ 3 Pasienten bodde i institusjon/sykehjem

☐ 9 Ukjent

Forflytning

☐ 1 Pasienten kunne forflytte seg alene/uten tilsyn, både inne og ute (bruk av hjelpemiddel tillatt)

☐ 2 Pasienten kunne forflytte seg alene/uten tilsyn inne, men ikke ute

☐ 3 Pasienten fikk hjelp av en annen person ved forflytning

☐ 9 Ukjent

Toalettbesøk

☐ 1 Pasienten klarte toalettbesøk alene

☐ 2 Pasienten klarte ikke toalettbesøk alene. Trengte hjelp til bruk av bekken eller bleie, eller trengte hjelp under toalettbesøket

☐ 9 Ukjent

Påkledning

☐ 1 Pasienten klarte av- og påkledning selv, også ytterklær, sko og strømper

☐ 2 Pasienten trengte hjelp med av- og påkledning

☐ 9 Ukjent

Funksjonsstatus

Modified Rankin Scale (Se egen veiledning) ☐ 0-6

Risikofaktorer før hjerneslaget

Tidligere hjerneslag?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, anfør type hjerneslag

☐ 1 Infarkt
☐ 2 Blødning
☐ 9 Ukjent
☐ 3 Uspesifisert
☐ 4 Både infarkt og blødning

Tidligere TIA? (Opplysninger om sikre tegn på TIA i form av klare forbigående fokale utfall)

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, når var siste TIA?

☐ 1 Innen siste uke
☐ 2 1-4 uker før slaget
☐ 3 4-12 uker før slaget
☐ 4 Over 12 uker før slaget

Tidligere hjerteinfarkt?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Gjennomgått store hjerte-/karintervensjoner?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, når?

☐ 1 Innen siste uke
☐ 2 1-4 uker før slaget
☐ 3 4-12 uker før slaget
☐ 4 Over 12 uker før slaget

Atrieflimmer bekreftet med EKG tidligere eller i løpet av innleggelsen (gjelder også paroxystisk atrieflimmer/flutter)**?**

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Diabetes, tidligere diagnostisert eller nyoppdaget?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Røykestatus

☐ 0 Aldri
☐ 1 Røyker
☐ 2 Eks-røyker (røykfri > 1 mnd)
☐ 9 Ukjent

Status i akuttfasen

Bevissthetsgrad ved innleggelsen

☐ 0 Våken
☐ 1 Døsig, reagerer adekvat ved lett stimulering
☐ 2 Døsig, reagerer først ved kraftig/gjentatt stimulering
☐ 3 Reagerer ikke, eller bare med ikke-målrettet bevegelse
☐ 9 Ukjent

Fokale utfall

Facialisparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Beinparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Andre nye fokale slagsymptomer

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Hvilke fokale symptomer?

☐ Ataksi
☐ Sensibilitetsutfall
☐ Neglekt
☐ Dobbeltsyn
☐ Synsfeltutfall
☐ Vertigo

Armparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Språk- eller taleproblemer

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

NIHSS (National Institutes of Health Stroke Scale)

Angi totalscore ved innkomst (innen 24 timer) ☐ ☐ Ikke utført

Cerebral CT eller MR ved innkomst (innen 12 t)?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Sidelokalisasjon av symptomer

☐ 1 Høyre ☐ 2 Venstre ☐ 3 Bilateralt ☐ 4 Ikke relevant ☐ 9 Ukjent

Medikamentell behandling før debut av hjerneslaget og ved utreise

Dersom det er dokumentert i journal/epikrise at pasienten starter med antikoagulasjon innen to uker etter symptomdebut av hjerneslaget kan det krysses av for antikoagulasjon ved utreise

Ved mors registreres alle medikamenter ved utreise som **Nei**

	Før debut av hjerneslaget			**Ved utreise**		
Medikament (Eksempler)	Ja 1	Nei 2	Ukjent 9	Ja 1	Nei 2	Ukjent 9
Acetylsalisylsyre (ASA) (Asasantin Retard, Acetylsalisylsyre, Albyl E, Aspirin, Axanum, Dispril, Globoid)	☐	☐	☐	☐	☐	☐
ADP-reseptorblokker (Brilique, Clopidogrel, Efient, Plavix)	☐	☐	☐	☐	☐	☐
Dipyridamol (Asasantin Retard, Persantin (Retard)):	☐	☐	☐	☐	☐	☐
Warfarin (Marevan)	☐	☐	☐	☐	☐	☐
Andre perorale antikoagulasjonsmidler enn Warfarin (Angiox, Arixtra, Eliquis, Novastan, Pradaxa, Xarelto)	☐	☐	☐	☐	☐	☐

Medikamentell behandling før debut av hjerneslaget og ved utreise, fortsettelse

	Før debut av hjerneslaget			Ved utreise		
	Ja 1	Nei 2	Ukjent 9	Ja 1	Nei 2	Ukjent 9
Diuretika (Aldactone, Atacand Plus, Benetor Comp, Burinex, Candemox Comp, Candesartan/ Hydrochlorothiazide, Centyl, CoAprovel, Corixil, Cozaar Comp, Diovan Comp, Diural, Enalapril Comp, Esidrex, Furix, Furosemid, Inspra, Irbesartan/Hydroklortiazid, Lasix Retard, Lisinopril/ Hydroklortiazid, Lodoz, Losartan/ Hydrochlorotiazide, Micardis Plus, Moduretic mite, Normorix mite, Olmetec Comp, Renitec Comp, Samsca, Spirix, Teveten Comp, Valsartan/ Hydrochlorotiazide, Zestoretic mite)	☐	☐	☐	☐	☐	☐
ACE-hemmer (Captopril, Enalapril, Enalapril Comp, Gopten, Lisinopril, Lisinopril/ Hydroklortiazid, Perindoprilarginin servier, Ramipril, Renitec, Renitec Comp, Triatec, Zanipress, Zestoretic, Zestoretic mite, Zestril, Zofenil, Zofenil Comp)	☐	☐	☐	☐	☐	☐
A2-antagonist (Alea. Amias, Aprovel, Atacand, Atacand Plus, Benetor, Benetor Comp, Candemox Comp, Candesartan, Candesartan/ Hydrochlorotiazide, CoAprovel, Corixil, Cozaar, Cozaar Comp, Diovan, Diovan Comp, Exforge, Irbesartan, Irbesartan/ Hydroklortiazid, Losartan, Losartan/Hydrochlorotiazide, Micardis, MicardisPlus, Olmetec, Olmetec Comp, Sevikar, Teveten, Teveten Comp, Valsartan, Valsartan/ Hydrochlorotiazide)	☐	☐	☐	☐	☐	☐
Betablokker (Atenolol, Bisoprolol, Brevibloc, Carvedilol, Emconcor, Hypoloc, Inderal Retard, Lodoz, Metoprolol, Pranolol, Seloken, Selo-zok, Sotalol, Tenormin, Trandate, Uniloc.)	☐	☐	☐	☐	☐	☐
Kalsiumantagonist (Adalat, Alea, Amlodipin, Cardizem, Exforge, Felodipin, Isoptin, Lerkandipin, Lomir, Nimotop, Norvasc, Plendil, Sevikar, Verakard, Zanidip.)	☐	☐	☐	☐	☐	☐
Statin og andre lipidsenkende (Atorvastatin, Cholestagel, Crestor, Ezetrol, Inegy, Lescol. Lestid, Lipitor, Lovastatin, Omacor, Pravachol, Pravastatin, Questran, Simvastatin, Sortis, Zocor)	☐	☐	☐	☐	☐	☐
Medikamentell behandling for høyt blodtrykk	☐	☐	☐	☐	☐	☐

Antikoagulasjonsbehandling under innleggelsen

	Ja 1	Nei 2	Ukjent 9
Antikoagulasjon med Heparin/lavmolekylært Heparin i.v. eller s.c. gitt som behandling av det akutte hjerneslaget (Atenativ, Enoksaparin, Fragmin, Hepaflex, Heparin, Innohep, Klexane)	☐	☐	☐
Antikoagulasjon med Heparin/lavmolekylært Heparin i.v. eller s.c gitt som profylakse og/eller behandling mot DVT og eventuell lungeemboli (Atenativ, Enoksaparin, Fragmin, Hepaflex, Heparin, Innohep, Klexane)	☐	☐	☐

Trombolytisk behandling

Trombolyse ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ☐

Starttidspunkt for trombolyse

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

NIHSS (Totalscore) *Før* trombolyse ☐ ☐ Ikke utført

NIHSS (Totalscore) 24 t *etter* trombolyse ☐ ☐ Ikke utført

Hjerneblødning med klinisk forverring innen 36 timer etter behandlingsstart tilsvarende 4 poeng eller mer på NIHSS (skal være verifisert med CT/MR eller obduksjon ☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Trombektomi

Er trombektomi eller annen endovaskulær behandling gjennomført? ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ☐

Starttidspunkt for trombektomi

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

NIHSS (Totalscore) *Før* trombolyse ☐ ☐ Ikke utført

NIHSS (Totalscore) 24 t *etter* trombektomi ☐ ☐ Ikke utført

Hemikraniektomi

Er hemikraniektomi gjennomført? ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ☐

Starttidspunkt for hemikraniektomi

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

Behandlingskjeden

Symptomdebut
Angi tidspunkt for symptomdebut. Dersom pasienten vaknet med symptom angis siste tidspunkt uten sypmtom, for eksempel ved leggetid

☐☐ ☐☐ ☐☐ ☐☐ ☐☐
Dato Måned År Timer Min

Våknet pasienten med symptom på hjerneslag?
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Innleggelsestidsunkt

☐☐ ☐☐ ☐☐ ☐☐ ☐☐
Dato Måned År Timer Min

Hvor oppsto hjerneslaget?
☐ 1 Utenfor sykehus
☐ 2 I sykehus, ikke prosedyrerelatert
☐ 3 I sykehus, prosedyrerelatert

Ble AMK/ambulanse varslet?
☐ 1 Ja
☐ 2 Nei
☐ 3 Ukj.

Transportmetode
☐ 1 Ambulanse
☐ 2 Luftambulanse
☐ 3 Kombinasjon av ambulanse og luftambul.
☐ 4 Annet

Avdeling/enhet først innlagt?
☐ 1 Slagenhet (se veiledning)
☐ 2 Annen sengeavdeling

Hvilken avdeling?
☐ 1 Medisinsk
☐ 2 Nevro
☐ 3 Nevrokirurgi
☐ 4 Intensiv/ annen overvåkingsavd.
☐ 5 Observasjon
☐ 6 Annen

Overflyttet fra sykehus
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvilket sykehus?
☐

Dato overflyttet fra sykehus
☐☐ ☐☐ ☐☐
Dato Måned År

Hvilke undersøkelser og tiltak er utført under oppholdet?

Bildediagnostikk av hjerneslaget
☐ 1 Ingen
☐ 2 CT
☐ 3 MRI
☐ 4 CT + MRI
☐ 5 Annen
☐ 9 Ukjent

Bildediagnostikk av ekstrakranielle kar
☐ 1 Ingen
☐ 2 Ultralyd
☐ 3 CT-angio
☐ 4 MR-angio
☐ 5 Kombinasjon
☐ 9 Ukjent

Bildediagnostikk av intrakranielle kar
☐ 1 Ingen
☐ 2 Ultralyd
☐ 3 CT-angio
☐ 4 MR-angio
☐ 5 Kombinasjon
☐ 9 Ukjent

Bildediagnostikk av hjerte
☐ 1 Ingen
☐ 2 Transthorakal ultralyd. Ecco cor
☐ 3 Transøsofageal ultralyd. Ecco cor
☐ 4 MRI
☐ 5 Kombinasjon av flere
☐ 6 Annen
☐ 9 Ukjent

Registrering av hjerterytme
☐ 1 Ingen
☐ 2 EKG
☐ 3 Telemetri/kontinuerlig EKG monitorering
☐ 4 Holtermonitorering
☐ 5 Kombinasjon av flere
☐ 9 Ukjent

Er fysiologisk homeostase kontrollert og behandlet i henhold til sjekkliste for pasientsikkerhetsprogrammet?
☐ 1 Ja
☐ 2 Nei
☐ 3 Ikke relevant
☐ 9 Ukjent

Er svelgfunksjonen vurdert/testet?
☐ 1 Ja
☐ 2 Nei
☐ 3 Ikke relevant
☐ 9 Ukjent

Er pasienten mobilisert ut av seng i løpet av de første 24 timer etter innleggelsen?
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Har pasienten fått en tverrfaglig vurdering?
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Utskriving

Utskrivingsdato
☐☐ ☐☐ ☐☐
Dato Måned År

Avdeling/enhet utskrevet fra?
☐ 1 Slagenhet (se veiledning)
☐ 2 Annen sengeavdeling

Hvilken avdeling?
☐ 1 Medisinsk
☐ 2 Nevrologisk
☐ 3 Nevrokirurgisk
☐ 4 Intensiv / annen overvåkingsavdeling
☐ 5 Observasjonsavdeling
☐ 6 Annen avdeling

Utskrives til
☐ 1 Egen bolig uten hjemmesykepleie/ hjemmehjelp
☐ 2 Egen bolig med hjemmesykepleie/ hjemmehjelp
☐ 3 Omsorgsbolig med døgnkontinuerlige tjenester og personale
☐ 4 Sykehjem
☐ 5 Annen avdeling for videre behandling
☐ 6 Annen avd. i påvente av sykehjem/rehab.
☐ 7 Rehabiliteringsavdeling/-institusjon - inkludert rehabilitering i sykehjem
☐ 8 Opptreningssenter
☐ 9 Ukjent
☐ 10 Død i løpet av oppholdet
☐ 11 Annet - spesifiser

Mors

Morsdato
☐☐ ☐☐ ☐☐
Dato Måned År

Obdusert?
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Er pasienten fulgt opp av et tverrfaglig team i forbindelse med utskriving fra sykehus?
☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, sett ett kryss
☐ 1 Team organisatorisk tilknyttet sykehus
☐ 2 Team organisatorisk tilknyttet kommune

Appendix 7

Follow-up registrations at three months from the National Norwegian Stroke Registry

Norsk hjerneslagregister

Oppfølgingsskjema 2015

Anvendes ved 3 måneders registrering av akutte hjerneslag innlagt fra og med 01.01.2015

Personnummer ☐☐☐☐☐☐☐☐☐☐☐

Telefon ____________

Navn ____________

Pasientstatus

Oppfølgingsdato

☐☐ Dato ☐☐ Måned ☐☐ År

Boligforhold

- ☐ 1 Egen bolig uten hjemmesykepleie/hjemmehjelp
- ☐ 2 Egen bolig med hjemmesykepleie/hjemmehjelp
- ☐ 3 Omsorgsbolig med døgn døgnkontinuerlige tjenester og personale
- ☐ 4 Sykehjem
- ☐ 9 Ukjent

Sivilstatus

- ☐ 1 Gift/samboende
- ☐ 2 Enke/enkemann
- ☐ 3 Enslig
- ☐ 9 Ukjent

Bosituasjon

- ☐ 1 Bor alene
- ☐ 2 Bor sammen med noen (f.eks. ektefelle/samboer, søsken, barn)
- ☐ 3 Bor i institusjon/sykehjem
- ☐ 9 Ukjent

Innlagt sykehus etter utskriving
(flere alternativer mulig)

- ☐ 1 Hele tiden innlagt
- ☐ 2 Reinnlagt for nytt slag
- ☐ 3 Reinnlagt annen årsak
- ☐ 4 Ikke reinnlagt

Er du operert i halspulsåre?

- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Ukjent

Rehabiliteringstiltak etter utskriving (flere alternativer mulig)

- ☐ 1 Døgnopphold i rehab.avd.
- ☐ 2 Opptreningssenter
- ☐ 3 Døgnrehabilitering i sykehjem
- ☐ 4 Dagrehabilitering
- ☐ 5 Hjemmerehabilitering
- ☐ 6 Rehabilitering i fysikalsk institutt
- ☐ 7 Behandling hod logoped
- ☐ 8 Annet (spesifiser) ____________
- ☐ 9 Ukjent

Spesifiser

- ☐ 1 Infarkt
- ☐ 2 Blødning
- ☐ 9 Ukjent

Spesielle funksjoner

Hjelp i daglige gjøremål (ADL)
(flere alternativer mulig)

- ☐ 1 Ingen
- ☐ 2 Familie
- ☐ 3 Hjemmehjelp
- ☐ 4 Hjemmesykepleie
- ☐ 5 Institusjon
- ☐ 6 Andre

Forflytning

- ☐ 1 Jeg kan forflytte meg alene/uten tilsyn både ute og inne.
- ☐ 2 Jeg kan forflytte meg alene/uten tilsyn inne, men ikke ute.
- ☐ 3 Jeg trenger hjelp av en annen person ved forflytning
- ☐ 9 Vet ikke / ukjent

Toalettbesøk

- ☐ 1 Jeg klarer toalettbesøk selv
- ☐ 2 Jeg klarer ikke toalettbesøk alene. Trenger hjelp til bruk av bekken eller bleie, eller trenger hjelp under toalettbesøk
- ☐ 9 Vet ikke / ukjent

Av-/påkledning

- ☐ 1 Jeg klarer av-/påkledning selv, også ytterklær, sko og strømper
- ☐ 2 Jeg trenger hjelp med av-/påkledning
- ☐ 9 Vet ikke / ukjent

Skjema fortsetter på andre siden

Oppfølging og livskvalitet

Har du problemer med å lese og skrive (som ikke var tilstede før hjerneslaget)?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Har du problemer med å svelge (som ikke var tilstede før hjerneslaget)?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Har du problemer med å snakke (som ikke var tilstede før hjerneslaget)?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Har du synsproblemer (som ikke var tilstede før hjerneslaget)?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Har du kommet deg helt etter hjerneslaget?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Har du fått tilstrekkelig hjelp etter hjerneslaget?

☐ 1 Ja
☐ 2 Nei
☐ 3 Har ikke behov
☐ 9 Vet ikke / ukjent

Har du fått så mye trening som du ønsker etter hjerneslaget?

☐ 1 Ja
☐ 2 Nei
☐ 3 Har ikke behov
☐ 9 Vet ikke / ukjent

Har du vært til legekontroll etter hjerneslaget?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Er du like fornøyd med tilværelsen etter hjerneslaget som før hjerneslaget?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Tar du medisin mot høyt blodtrykk?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Tar du blodfortynnende medisin mot blodpropp?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Tar du medisin mot høyt kolesterol?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Røykestatus

☐ 0 Aldri
☐ 1 Røyker
☐ 2 Eks-røyker (røykfri > 1 mnd)
☐ 9 Ukjent

Var du yrkesaktiv da du fikk hjerneslag?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Er du yrkesaktiv nå?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Kjørte du bil før du fikk hjerneslag?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Kjører du bil nå?

☐ 1 Ja
☐ 2 Nei
☐ 9 Vet ikke / ukjent

Funksjonsstatus (Modified Rankin Scale)

Sett kun ett kryss ved svaralternativet som best beskriver ditt funksjonsnivå

☐ 0 Ingen symtomer
☐ 1 Ingen betydningsfull funksjonssvikt til tross for symptomer, klarer å utføre alle oppgaver og aktiviteter som før
☐ 2 Lett funksjonssvikt; klarer ikke å utføre alle aktiviteter som før, men klarer sine daglige gjøremål
☐ 3 Moderat funksjonssvikt: trenger noe hjelp, men går uten hjelp
☐ 4 Alvorlig funksjonssvikt; klarer ikke å gå uten hjelp og klarer ikke å ivareta sine grunnleggende behov uten hjelp
☐ 5 Svært alvorlig funksjonssvikt; sengeliggende og trenger konstant tilsyn og hjelp
☐ 6 Død

Besvart av (flere alternativer mulig)

☐ 1 Pasient
☐ 2 Familie
☐ 3 Helsepersonell
☐ 4 Andre

Spesifiser ____________

Hvordan ble oppfølgingsskjema etter 3 måneder registrert?

☐ 1 Per telefon
☐ 2 Per brev
☐ 3 Ved besøk på poliklinikk

Appendix 8

Follow-up registrations adjusted for use in Denmark at three months

telefoninterview 3 mdr. efter apopleksi
Samarbejdsprojekter mellem Norge og Danmark

Patientoplysninger

ID nr.:

1 - Køn	Mand	1	Kvinde	2
2 - CPR nr.				
3 - Navn				
4 - Telefon				
5 - Telefon, pårørende				

Patientstatus

6 - Er opfølgningen udført	Ja	1	Nej	2
7 - Dato for opfølgning (dd.mm.åå.)				

8 - Årsag:	
Kan ikke træffes Antal henvendelser **mindst 20** _____	1
Ønsker ikke at svare	2
Afgået ved døden	3
Andet Skriv årsag: ______________________	4
Hemmeligt telefon nr.	5

9 - Boligforhold

Egen bolig uden hjemmehjælp eller hjemmesygepleje	1	
Egen bolig med hjemmehjælp eller hjemmesygepleje	2	Hvis borgeren har nødkaldeanlæg scores 3.
Ældre- eller handicapvenlig bolig med mulighed for tilkald af personale hele døgnet	3	Der scores 3 uanset om borgeren gør brug af muligheden for tilkald eller ej.
Plejehjem eller institution	4	Der scores kun 4 såfremt borgeren har ***fast*** bopæl på plejehjem eller institution. Ved aflastning scores de boligforhold borgeren ellers bor i.
Ukendt	9	

10 - Samlivsstatus

Gift eller samlevende	1
Enke eller enkemand	2
Enlig	3
Ukendt	9

11 - Boligsituation

Bor alene	1	
Samboende (fx ægtefælle, samlever, søskende, barn)	2	
Bor på institution eller plejehjem	3	Der scores kun 3 såfremt borgeren har ***fast*** bopæl på plejehjem eller institution. Ved aflastning scores de boligforhold borgeren ellers bor i.
Ukendt	9	

Udarbejdet juli 2013 af Guri Heiberg, Audny Anke og Henriette Holm Stabel med baggrund i Norsk Hjerneslagsregister version 3.0.

12 - Genindlæggelse

Har været indlagt hele tiden	1
Genindlagt for ny apopleksi	2
Genindlagt af anden årsag	3
Ikke genindlagt	4

13 - Specificer:	
Blodprop	1
Blødning	2
Ukendt	9

14 - Rehabilitering efter udskrivelse

Døgnrehabilitering på specialiseret afd. med tværfaglige medarbejdere (Sygehuse, Vejlefjord, RHN, Skive og lign.)	1
Specialiseret dagrehabilitering med tværfaglige medarbejdere (Hjerneskadecentrene, Voksen Special tilbud, Kommunal jobafklaring og lign.)	2
Kommunalt dagcenterehabilitering	3
Hjemmerehabilitering /hverdagsrehabilitering ved hjemmehjælp efter introduktion fra ergo- og/eller fysioterapeut	4
Hjemmerehabilitering /hverdagsrehabilitering ved ergo- og/eller fysioterapeut	5
Behandling og/eller træning ved privat praktiserende fysioterapeut	6
Andet Skriv hvad: ________________________________	7
Ingen rehabilitering efter udskrivelse	8
Ukendt	9

15 - Navn på rehabiliteringssted	**16** - Dato for indlæg.	**17** - Dato for udskriv.	**18** – Udskrevet til	**15a – antal uger**
a:				
b:				
c:				
d:				

19 - Blev du overflyttet fra apopleksiafd. og direkte til videre døgn-rehabilitering	
Ja	1
Nej – ***hvis nej besvares også nedenstående***	2

20 - Hvor lang tid gik der fra, at du blev udskrevet fra sygehuset, til du påbegyndte videre specialiseret døgnrehabilitering?	
Indenfor 1 uge	1
Indenfor 2 uger	2
Indenfor 3 uger	3
Indenfor 4 uger	4
Mere end 4 uger	5

Såfremt borgeren har modtaget anden rehabilitering end døgnrehabilitering markeres rehabiliteringstilbudet ***i ét af de grønne felter***. De grønne pile følges herefter, så hvert rehabiliteringstilbud registreres.

21 - Hvor lang tid gik der fra, at du blev udskrevet fra sygehuset, til du påbegyndte videre rehabilitering?	
Indenfor 1 uge	1
Indenfor 2 uger	2
Indenfor 3 uger	3
Indenfor 4 uger	4
Mere end 4 uger	5

Specificering af behandlings- eller rehabiliteringstiltag i kommunalt regi som patienten har modtaget efter udskrivelsen

Har du modtaget behandling eller rehabilitering fra......

22 - Fagperson	**Ja**	**Nej**	**23 - Rehabiliteringstilbud (skriv tal fra boks med rehabiliterings ovenfor)**	**24 – Dato start**	**25 – Dato slut**	**Antal uger**	**26 - Fortsat tilbud? (Ja/Nej)**	**27 - Timer pr. uge**	**28 - Dage pr. uge**
Sygeplejerske									
Fysioterapeut									
Ergoterapeut									
Logopæd									
Andre faggrupper (fx psykolog)									
29 - Har du trænet hjemme alene? (ingen fagpersoner har været involveret)									
Hjemmetræning alene									

Udarbejdet juli 2013 af Guri Heiberg, Audny Anke og Henriette Holm Stabel med baggrund i Norsk Hjerneslagsregister version 3.0.

Udvalgte funktioner

30 - Hjælp i dagligdagen (mulighed for at markere flere svar)	
Ingen hjælp	1
Hjælp fra familie	2
Hjemmehjælp	3
Hjemmesygepleje	4
Institution / plejehjem	5
Andre	6

31 - Forflytning	
Jeg kan forflytte mig selv alene og uden opsyn både ude og inde	1
Jeg kan forflytte mig selv alene og uden opsyn inde, men ikke ude	2
Jeg behøver hjælp fra andre til forflytninger	3
Ved ikke / ukendt	9

32 - Toiletbesøg	
Jeg klarer toiletbesøg selv	1
Jeg kan ikke klare toiletbesøg selv; behov for hjælp, bruger bækken / bleer	2
Ved ikke / ukendt	9

33 - Af- og påklædning	
Jeg klarer selv af- og påklædning, herunder overtøj, sko og strømper	1
Jeg har behov for hjælp til af- og påklædning	2
Ved ikke / ukendt	9

Opfølgning på din rehabilitering og livskvalitet

34 - Har du sprog og/eller taleproblemer efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9

35 - Har du problemer med synet efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9

36 - Er du kommet dig helt efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9

37 - Har du modtaget tilstrækkelig hjælp i det daglige efter din apopleksi?	
Ja	1
Nej	2
Har ikke behov for hjælp	3
Ved ikke / ukendt	9

38 - Har du modtaget så meget træning, som du har ønsket efter din apopleksi?	
Ja	1
Nej	2
Har ikke behov for hjælp	3
Ved ikke / ukendt	9

39 - Har du været til lægekontrol efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9

40 - Er du lige så tilfreds med tilværelsen, som du var før din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9

41 - Tager du medicin mod for højt blodtryk?	
Ja	1
Nej	2
Ved ikke / ukendt	9

42 - Tager du blodfortyndende medicin?	
Ja	1
Nej	2
Ved ikke / ukendt	9

Udarbejdet juli 2013 af Guri Heiberg, Audny Anke og Henriette Holm Stabel med baggrund i Norsk Hjerneslagsregister version 3.0.

43 - Tager du medicin mod for højt kolesterol?	
Ja	1
Nej	2
Ved ikke / ukendt	9
44 - Tager du medicin mod grådlabilitet, depression eller nedsat humør (SSRI præparater)	
Ja	1
Nej	2
Ved ikke / ukendt	9
45 - Ryger du eller har du røget tidligere?	
Nej - har aldrig røget	1
Ja - ryger	2
Ja - er eks-ryger (røgfri > 1 mdr.)	3
Ukendt	9
46 - Var du aktiv på arbejdsmarkedet før du fik din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
47 - Er du aktiv på arbejdsmarkedet nu?	
Ja	1
Nej	2
Ved ikke / ukendt	9
48 - Kørte du bil før du fik din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
49 - Kører du bil nu?	
Ja	1
Nej	2
Ved ikke / ukendt	9

50 - Besvarelse

Interview er foretaget med: (mulighed for at markere flere svar)	
Patient	1
Familie	2
Sundhedsfagligt personale	3
Andre Skriv hvem:____	4

51 - Status for funktionsniveau – Modified Rankin Scale

Status efter apopleksi	
Ingen symptomer overhovedet	0
Ingen synlig funktionsnedsættelse Lette symptomer, men ingen helbredsgener i det daglige, trods symptomer. Udfører de samme gøremål som tidligere	1
Nogen funktionsnedsættelse Mindre handicap. Overkommer mindre end tidligere. Opgivet gøremål pga. helbredet. Klarer sig selv uden hjælp	2
Moderat funktionsnedsættelse Moderat handicap. Behøver let hjælp til daglige gøremål	3
Moderat til svær funktionsnedsættelse Behøver meget hjælp til personlig hygiejne, toiletbesøg og andre daglige gøremål	4
Svær Funktionsnedsættelse Behøver konstant opsyn, er sengeliggende, inkontinent, er afhængig af, at der er nogen næsten hele tiden	5
Ukendt	6

Appendix 9

Information and consent – paper II

Forespørsel om deltakelse i forskningsprosjektet

«Sammenheng mellom rehabiliteringsforløp og livskvalitet ett år etter hjerneslag i Norge og Danmark. En mixed method studie»

Bakgrunn og hensikt
Dette er et spørsmål til deg om å delta i en forskningsstudie for å få mer kunnskap om hvordan helsetjenestetilbudet på best mulig måte kan legges opp for å hjelpe personer som har hatt hjerneslag til å få en best mulig hverdag. Studien søker innsikt i hva pasienter selv synes er viktig for å kunne leve et godt liv etter hjerneslag og om og hvordan de mener at helsepersonell og andre har bidratt til dette. Forespørselen rettes til deg fordi du har hatt et hjerneslag for ett år siden og gjort erfaringer med helsevesenet og det å leve med hjerneslag. Prosjektet utgår fra Universitetssykehuset i Nord-Norge og er et samarbeidsprosjekt mellom Universitetet i Tromsø og Hammel Neurocenter, Danmark.

Hva innebærer studien?
Deltakelse i studien vil innebære en samtale med deg i form av et intervju. Intervjuet vil ha en varighet på vel en time og kan gjøres hjemme hos deg eller et annet avtalt sted. Intervjuet vil bli tatt opp på lydbånd.

Mulige fordeler og ulemper
Fordelen med å delta i studien er at du bidrar med viktig kunnskap som kan bedre rehabiliterings-tilbudet til personer med hjerneslag. Studien medfører ikke mer tids- og ressursbruk av deg enn vel en times intervju. Som forskere har vi et særlig ansvar for at intervjuet skal oppleves positivt og ikke som en merbelastning for deg.

Hva skjer med informasjonen om deg?
Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Samarbeidspartnerne i studien vil kun ha tilgang til de avpersonifiserte opplysningene. Denne studien er en del av en større studie «Rehabiliteringsforløp, funksjon og livskvalitet etter hjerneslag i Norge og Danmark. En internasjonal multisenterstudie» som du allerede har samtykket i å delta i. Opplysninger om deg fra hjerneslagsregisteret og spørreskjema du har svart på ved 3 og 12 måneder vil bli sett i sammenheng med dette intervjuet. Innhentet informasjon om deg vil bli slettet etter prosjektslutt den 18.08. 2018. Resultatene vil bli publisert i internasjonale tidsskifter. Det vil så langt som mulig søkes å publisere resultatene slik at ikke identiteten til inkluderte kommer frem.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektleder Cathrine Arntzen på 92616852 eller stipendiat Synne Garder Pedersen på 91838630.

Personvern
Opplysninger som registreres om deg er om dine erfaringer med å leve med hjerneslag, hva som er viktig for å kunne leve et godt liv og dine erfaringer med helsevesenet. Alle som får innsyn har

taushetsplikt. Universitetssykehuset i Nord-Norge ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre
Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til Hammel Neurocenter, Danmark.

Rett til innsyn og sletting av opplysninger om deg
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien
Som deltakerne har rett til å få informasjon om resultatet av studien. Studien vil bli publisert i internasjonale tidsskrift og mulig omtalt i populærvitenskapelige tidsskrifter. Ved henvendelse kan du få tilsendt materiale fra studien.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 10

Interview guide

Interview guide for the "NORDA-study"
Follow-up interview one-year after stroke

Research-themes	Related questions
Experiences of everyday life management following stroke	• Looking back over the last couple of weeks, is there anything you would like to discuss with me, or anything you would like me to know? • How do you feel about being back home? How do you feel about your current situation? • Please describe a typical day (activities, day-to-day tasks, pleasures) Follow-up question: Are there things that you miss in your everyday life? • Do you feel differently about your situation since the last time we spoke? (3months after rehabilitation-admittance) • Looking back at your rehabilitation-stay, what have been most significant for your returning home? • Have you experienced anything that surprised you after returning home (positive or negative)? • Are there special episodes/situations from the rehabilitation-pathway that come to mind and that have been important for dealing with everyday life after returning home? • Have the health services that have been offered to you, helped you deal with daily tasks in a better way? If so, in what way/s? • Have you, your family or health care personnel developed solutions that make everyday life easier? • How do you think that you and your closest family have coped with your situation following your stroke? • Are there certain things in the rehabilitation-pathway that you did not see the purpose of during treatment, but that you look at differently today? • Looking back, are there things you would do or would prioritized differently during your time in rehabilitation? • Is there anything in your current situation that you think could be improved? Can you think of any solutions? Who do you think could help you solve these issues? • Could other people in the same situation as you learn anything from your experiences? Please elaborate. • Has your health situation changed your plans, hopes, thoughts or wishes for the future? • What do you think your life will be like in three to five years from now?
Life dimensions related to experience of quality of life	• How do you feel right now? • What can you tell me about your life today? • Could you describe what a good life means to you? Follow-up question: Do you experience your life like that now? Follow-up question: What makes (or does not make) it possible to live the way you would like to? • Are there things in life that have become more, or less, important to you? • Do you prioritize differently now compared to before your stroke? • What do you think is essential to making you feel good? • Overall, what do you think has made a particular impact on your life situation today? • Looking back at the past year, could you, the health care system or others, have done anything to improve how you are today? • Looking back at your life before you had the stroke, and your life following stroke – do you experience a different outlook on life? • Did you learn anything about life as a consequence of experiencing a stroke?