UiT The Arctic University of Norway

Faculty of Health Sciences

Department of Health and Care Sciences

Stroke rehabilitation

A mixed method study evaluating a novel physiotherapy intervention and patients' experiences

Marianne Sivertsen

A dissertation for the degree of Philosophiae Doctor March 2023

Acknowledgements

The last four years have been a journey of learning that has been inspiring, fun, steep and at times overwhelming. I am deeply grateful for this opportunity. It has been a privilege to be able to deep-dive into an area that has interested and engaged me for many years.

This thesis is based on research conducted in hospitals, rehabilitation units, municipalities and in the participants homes between the autumn of 2019 and 2021. I would like to express my gratitude to all the participants and collaborators that made this project possible. Words cannot express my sincere appreciation to the participants who chose to partake during very difficult times in their lives. Many thanks to all the physiotherapists who have made this project possible through investing time and effort on top their busy clinical caseloads. Some in recruiting participants, others in meticulous testing, or in participating in training and providing physiotherapy treatment. The leaders in the physiotherapy departments at the hospitals, the rehabilitation units and municipalities involved deserve a thank you for their commitment and for providing the infrastructure needed to complete this project.

I would like to thank the Northern Norway Regional Health Authority for funding the project, the Department of Health and Care Sciences at the University of Tromsø where this PhD has been conducted and Nordland Hospital trust for being my employer.

I could not have done this without my supervisors Britt Normann, Karl Bjørnar Alstadhaug and Ellen Christin Arntzen. Your knowledge and skills, enthusiasm, encouragement and patience has been invaluable, and I have learned so much. To Britt, this project is a result of your endless creativity, engagement and knowledge. Thank you for encouraging me to embark on this journey and for your continuous support.

Most importantly, to my family, friends and colleagues, having such good people in my life mean everything. A special thank you to Håvard, Magnus and Sindre for supporting me, cheering, listening, and for the joy and love you bring to my life.

Table of Contents

Abstract

Background: Rehabilitation after stroke is a complex multidisciplinary process, and physiotherapy is important in optimising body functions, activities and participation. This thesis addresses the possible benefits and challenges regarding taking part in a comprehensive individualized physiotherapy intervention, called I-CoreDIST and usual care physiotherapy following an acute stroke along with patient perceptions of participation along the rehabilitation continuum

Methods: This is a mixed method study consisting of a randomised controlled trial (RCT) and an in-depth interview study. Sixty participants with acute strokes were recruited for the RCT and randomised into receiving I-CoreDIST or usual care physiotherapy for 12 weeks in equal doses. Assessments were undertaken at baseline and at 12 weeks post inclusion. Primary outcome measures were the Trunk Impairment Scale modified Norwegian version and ActiGraph Wgt3X-BT measurements of levels of physical activity. Secondary outcome measures were the Swedish Postural Assessment Scale for stroke -Norwegian Version, The Mini Balance Evaluation Systems Test, 10 metre walk test, 2 metre walk test, EQ-5D-3L and the Stroke Specific Quality of Life Scale (only conducted at 12 weeks). An intention-to-treat analysis was conducted using IBM SPSS (Statistics version 27 SPSS INC., Chicago IL). A multiple linear regression model was fitted to determine between-group differences. Within-group differences were calculated using paired samples t-test or Wilcoxon signed rank test. From the full sample, 19 participants were purposely selected for interviews. The interviews were transcribed verbatim, systematised using NVivo software, v12.6.0 (QSR International, 2019) and analysed using systematic text condensation. The findings from both the quantitative and qualitative analysis were integrated through extracting the main findings and identifying common themes, divergences and inconsistencies to highlight aspects related to the overall aim of the study that either study could not have alone.

Results: The integrated findings form three categories 1) *Transitions -enablers and challenges for participation:* the objective measures at baseline and at 12 weeks align with experiences of transitions from being able to becoming unable and re-enablement during rehabilitation. There were no statistically significant differences between groups in terms of postural control, physical activity, balance or gait at 12 weeks, except improvements on EQ-5D-3L in favour of the usual care group. Experiences of transfers through the different levels of the health care system are highlighted. 2) *Structures and traditions in institutions and municipalities shape delivery of care:* The inherent structures and cultures of hospitals, rehabilitation wards and municipality care shape practices of communication, decision-making and the delivery of clinical practices, including physiotherapy 3) *Meaning, progress and embodiment:* Experiencing positive bodily changes, individualization and intensity in training are linked to the development of meaning and motivation in physiotherapy. Both groups demonstrated significant improvements and were satisfied with physiotherapy follow-up. Carry-over of improvements on a body-structure level to activities and participation seem limited.

Conclusion: The integrated findings highlight the importance of thorough assessments of disability early after a stroke. There were improvements in both groups that align with experiences of becoming able indicating that participating in 12 weeks of intensive physiotherapy early after a stroke was beneficial regardless of group allocation. There were no between-group differences apart from higher scores in EQ-5D-3L in the usual care group. Variations in organisational structures and cultures shape different aspects of active patient participation in post-stroke rehabilitation. Meaning and motivation is connected to experiencing bodily changes and tailored treatment. Nevertheless, despite functional improvements, sustained inactivity is a challenge in long-term care.

List of papers

I. Sivertsen, M., Arntzen, E. C., Alstadhaug, K. B., & Normann, B. (2022). Effect of innovative vs. usual care physical therapy in subacute rehabilitation after stroke. A multicenter randomized controlled trial. *Frontiers in rehabilitation sciences*, *3*, 987601. https://doi.org/10.3389/fresc.2022.987601

II. Sivertsen, M., De Jaegher, H., Alstadhaug, K. B., Arntzen, E. C., & Normann, B. (2022). The precarity of patient participation - a qualitative interview study of experiences from the acute stroke and rehabilitation journey. *Physiotherapy theory and practice*, 1–16. Advance online publication. https://doi.org/10.1080/09593985.2022.2140319

III. Sivertsen, M., De Jaegher, H., Arntzen, E. C., Alstadhaug, K. B., & Normann, B. (2022). Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke: A qualitative study. *Physiotherapy research international: the journal for researchers and clinicians in physical therapy*, *27*(3), e1948. https://doi.org/10.1002/pri.1948

Abbreviations and definitions

ADL	Activities of Daily Living
BI	Barthel Index
CNS	Central Nervous System
DALY's	DALY's: Disability Adjusted Life Years. Combines years of life lost to premature mortality (YLL's) and years of healthy life lost due to disability (YLD's). One DALY represents the loss of the equivalent of one year of full health. DALY's for a disease or health condition are the sum of the years of life lost to YLL's and the YLD's due to prevalent cases of the disease or health condition in a population
HRQOL	Health Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
EBP	Evidence Based Practice
ESD	Early Supported Discharge
NIHSS	National Institute of Health Stroke Scale
MiniBESTest	Mini Balance Evaluation Systems Test
mRS	modified Rankin Scale
PROM's	Patient Reported Outcome Measures
RCT	Randomised Controlled Trial
SSQOL	Stroke Specific Quality of Life
SwePASS-NV	Swedish Postural Assessment Scale for stroke -Norwegian Version
TIS-modNV	Trunk Impairment Scale modified Norwegian Version
WHO	World Health Organization
2MWT	2 minute walk test
10MWT	10 metre walk test

1 Introduction

Rehabilitation after stroke is a complex multidisciplinary process, in which physiotherapy plays an essential role in optimising body functions, structures, activities and participation (Sehatzadeh, 2015). Individualised, evidence-based interventions that aim for recovery, continuity of services and high-quality studies, with both clinical endpoints and patient-reported outcomes, are called for (Boehme et al., 2021; Langhorne et al., 2009; Levin & Demers, 2020; Nielsen et al., 2015). This thesis addresses the possible benefits and challenges of participation in a new physiotherapy intervention, I-CoreDIST[1] and usual care physiotherapy after discharge from a stroke unit as well as experiences of patient participation during the first 12 weeks of the post-stroke rehabilitation trajectory. In doing so, we have applied a mixed methods approach, combining a prospective randomised controlled trial (RCT) assessing effects on postural control, balance, gait, physical activity and health related quality of life (HRQOL) and in-depth interviews exploring the participants' experiences. The integrated findings from these studies generate new knowledge regarding the influences of governance, institutional traditions along with interpersonal and individual factors upon delivery of rehabilitation services.

Stroke is the third leading cause of adult disability worldwide with an estimated 12.2 million incidence cases, 101 million prevalent cases and 143 million disability-adjusted-life-years (DALY's) in 2019 (GBD 2019 Stroke Collaborators, 2021). As a result of substantial research on how to best organise stroke care in the 1990s (Langhorne, 2021), guidelines covering acute incidences and early rehabilitation in stroke units and along the rehabilitation continuum are available internationally (Owolabi et al., 2021). There is a consensus that multidisciplinary rehabilitation, including physiotherapy, yields better results than no rehabilitation and that there is a positive correlation between dose of training and outcome (Dobkin, 2005). In addition,

---

[1] [1] I-CoreDIST: I= individualised, Core=trunk, D=dual task, I= intensive, S= specific, stability, somatosensory stimulation, T= teaching, training. Individualised Core activation combined with DISTal functional movement

there is evidence of a particularly beneficial, but not exclusive, window of opportunity for recovery within the first three to six months after a stroke (Bernhardt, Hayward, et al., 2017; Dobkin & Carmichael, 2016; Hordacre et al., 2021). Our understanding of the biological processes and psychosocial support required for recovery from stroke is incomplete (Bernhardt et al., 2020), and optimal stroke rehabilitation is still an equation with multiple unknowns. Conforto et al. (2022) argue that the major challenge for rehabilitation sciences, is to bridge the gaps between "the mechanisms of plasticity, prediction of outcome, relationships between behaviour and neurophysiological or imaging biomarkers and the development of interventions that lead to meaningful effects from the perspective of persons affected by stroke" (p. 4). Meaning and motivation are central to compliance and also directly linked to neuroplastic processes of recovery (Brodal, 2010; Danzl et al., 2012; Levin & Demers, 2020; Newell & Verhoeven, 2017). In addition to knowledge from neuroscience and clinical trials there is a need for a framework that incorporates the subjective perspective and a focus on what constitutes meaning alongside objective measures in research and clinical practice.

Geographical and sociodemographic inequalities exist both in the provision of and use of rehabilitation services (Bernhardt et al., 2020; GBD 2019 Stroke Collaborators, 2021; Owolabi et al., 2021). Even in high-income countries, meeting the recommendations of the guidelines in terms of the multidisciplinary organisation and high dosage of post-stroke care is a challenge when held up against the capacity and requirements for efficiency in health care (Adeoye et al., 2019). In Norway, unclear divisions of responsibility and fragmentation of care between municipality and specialist levels of health care along with geographical variations in services, are-well known challenges in rehabilitation (The Norwegian Directorate of Health, 2021). Municipalities vary greatly in terms of area, infrastructure, demography and access to multidisciplinary competency (Northern Norway Regional Health Authority, 2021). Some of the improvements in short-term outcomes gained from the by progress made in early stroke therapy may be lost in the long run due to unmet needs (Boehme et al., 2021). Critics argue that stroke is a chronic health condition, often managed like an acute illness (Scrivener et al., 2022). There is a need for coordination of the immediate follow-up, such as physiotherapy after stays in the stroke unit to ensure access to duration of care. In addition, there is a need for competency in neurological physiotherapy in the municipalities (The Ministry of Health and Care Services, 2011b). Interventions that build on the current knowledge of recovery and promote the continuity of care could reduce fragmentation and improve the quality of services.

In physiotherapy, considerable research gaps exist regarding the most beneficial approaches in terms of aiming to reduce post-stroke impairments. Generalised recommendations supported by sound evidence endorse an individualised, goal-directed approach, high doses of training and task-related practice (Pollock et al., 2014). However, a number of systematic reviews and meta-analyses of specific treatment approaches are inconclusive, mostly due to few, low-quality or inconclusive trials. Evidence-based interventions that aim for recovery are called for (Langhorne et al., 2009; Levin & Demers, 2020; Nielsen et al., 2015). Such interventions need to include measures that promote and evaluate levels of physical activity, and participation as these often remain low even when an individual’s functional recovery is satisfactory (Danielsson et al., 2014; Ferreira et al., 2022). Patients’ perceptions of health care quality have become an important part of quality measurements and an extension of standardised outcomes (Alexandrov et al., 2019; The Norwegian Directorate of Health, 2012). Investigations into patient experiences after stroke have illuminated new perspectives on post-stroke disability, such as various aspects of loss connected to bodily dysfunction and related to identity, self and roles (Arntzen, Borg, et al., 2015; Arntzen, Hamran, et al., 2015; Pallesen, 2014; Roenn-Smidt et al., 2021). New interventions should embrace the complexity of post-stroke disability through equipping patients with a comprehensive understanding of their post-stroke bodies transcending the traditional biomedical divide between the animate body and consciousness.

To meet the need for structured coordination of physiotherapy along the rehabilitation continuum, the utilisation of the neuroplastic window of opportunity, individualisation, dose and intensity, we have developed a novel physiotherapy intervention, called I-CoreDIST. The intervention targets trunk control in interaction with distal functional movement to mimic the requirements of everyday function, including increasing levels of physical activity. The implementation is low cost and aims to accompany the patient throughout different levels of health care. To examine the user experiences and effects of participation in I-CoreDIST and usual care physiotherapy we performed an RCT complemented by interviews with the participants. Our aim was to gain knowledge of the effect and experiences with the new intervention and usual care physiotherapy, as well as of patient perceptions of participation and roles in the rehabilitation continuum. To generate new knowledge from participants' experiences, that exceeds the actual situations (Malterud, 2015), concepts from enactive theory have been used as analytical tools. The enactive position provides subjectivity to the body and adopts a view of the body, the brain and the environment as a unity (De Jaegher & Di Paolo, 2007) which may elevate new aspects of the consequences of a stroke and participation in post-stroke rehabilitation.

In the following, I will present background information on stroke and post-stroke rehabilitation, including the organisation of stroke care in Norway. This will be followed by an outline of the resulting disability and the restoration of motor function after a stroke, including the available evidence for physiotherapy and theoretical frameworks. These chapters form the basis for this study and will be followed by a presentation of the aim and research question, methods used, results from the three papers, the integrated results and discussion.

2 Stroke and principles of post-stroke rehabilitation

A stroke is caused by an acute interruption of regional blood flow in the brain which causes cell death in the affected areas. The two most common types are 1) an ischemic stroke, caused by a blocked artery and 2) haemorrhagic stroke, caused by the bursting of a blood vessel, (World Health Organization, 2018). In 2021, 9158 strokes were registered in the Norwegian Stroke Registry (The Norwegian Stroke Registry, 2022). Of these, 85% were ischemic and 14% were haemorrhagic. The mean age was 77 years old for women (45%) and 72 years old for men (55%).

A disruption of cerebral blood flow may cause a variety of motor, sensory and cognitive symptoms depending on the location of the vessel occlusion or haemorrhage in the central nervous system (CNS). In the acute stage, if indicated, acute treatments such as thrombolysis or a thrombectomy may be administered (The Norwegian Directorate of Health, 2017). These are treatments that aim to restore circulation and thus brain function, particularly in the penumbra, which is the compromised, but viable tissue surrounding the irreversibly damaged ischemic core (Liu et al., 2010). The most common symptoms of a stroke are hemiparesis, hemisensory loss, loss of trunk control, visual loss, aphasia, ataxia, apraxia, deficits in coordination and cognitive issues with for example memory, personality changes and fatigue (Yew & Cheng, 2009). Several of which lead to challenges with postural control, balance and gait causing difficulties with independence in activities of daily living (ADL) and participation. The heterogeneity of such impairments calls for individualised physiotherapy interventions.

While the overall incidence and death rates have decreased because of successful developments in acute treatments and modification of risk factors, particularly in developed countries, the overall burden remains high and will probably rise due to population growth and ageing (GBD 2019 Stroke Collaborators, 2021). The major risk factors for experiencing a stroke are high blood pressure, high age, air pollution, diabetes, heart and blood vessel diseases, high cholesterol, and smoking (GBD 2019 Stroke Collaborators, 2021). Modifiable risk-factors account for about 90% of all strokes (O'Donnell et al., 2016), many of which can be reduced through a healthy diet, smoking cessation and physical activity. The rate of recurrent strokes is high (Zheng & Yao, 2019). Physiotherapy that aims to promote physical activity and a healthy lifestyle through functional recovery and education is important for secondary prevention.

Effective rehabilitation can decrease the burden of disability after a stroke and is defined as: a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environments (World Health Organization, 2017). Early mobilisation should commence between 24 and 48 hours after the stroke if the patient is hemodynamically stable (Langhorne et al., 2017) and aim to support recovery, reverse the negative effect of bedrest and increase survival rates. The minimum intensity and timing of rehabilitation are yet to be determined (Viruega & Gaviria, 2022). However, large trials investigating optimal intensity and dose are currently ongoing (Bernhardt et al., 2023).

Rehabilitation typically commences in a hospital stroke unit and is continued in an inpatient rehabilitation facility or outpatient/domiciliary setting. A stroke unit administers the focused care for people who have had strokes in a hospital under a multidisciplinary team of individuals who specialise in stroke management (Langhorne & Ramachandra, 2020). Treatment in a stroke unit has become the gold standard and result in lower mortality rates and reduce the loss of function after a stroke regardless of age and stroke severity (Langhorne & Ramachandra, 2020). Key to the stroke unit is the close multidisciplinary work and set structures for assessments, treatments and therapy, the use of standardised outcome measures and multidisciplinary meetings (The Norwegian Directorate of Health, 2017). Stoke units mark the start of the rehabilitation trajectory following a stroke, and yet, patients' views of their active participation in this early stage of rehabilitation have not been investigated to a large extent.

2.1 Organisation of stroke care in Norway

While acute stroke treatments and stroke unit care take place in hospital settings, inpatient rehabilitation units exist both within specialist and municipal settings. In 2021, the average length of stay in a stroke unit in Norway was 6.5 days (The Norwegian Stroke Registry, 2022). Typically, inpatient rehabilitation at a specialist level is offered to patients of working age with complex rehabilitation needs. In 2021, 24.4% of patients in Norway were referred to an inpatient rehabilitation facility when discharged from the stroke unit, 35.6% were discharged to their home without help and 11.8% were discharged to their home with help. The remaining patients were discharged to a nursing home or assisted living facility, to another hospital or died during admission (7.1%) (The Norwegian Stroke Registry, 2022). Outpatient physiotherapy services at a municipal level, often consist of both domiciliary services or treatment in outpatient clinics.

Access to coordinated multidisciplinary services in the community is variable; for example, not all municipalities provide occupational and speech therapy (Northern Norway Regional Health Authority, 2021) and there is a shortage of competency in neurological physiotherapy (The Ministry of Health and Care Services, 2011b). A coordination reform, implemented in Norway in 2012, shifted more responsibility for health care from the hospital sector to the municipalities. The aims of this reform were to accelerate assessment, treatment and discharge from hospital and strengthen the capacity and competency of the municipalities, supported by financial incentives (The Ministry of Health and Care Services, 2009). Knowledge is limited with regards to how patients perceive these transitions and their role in such decision-making throughout the rehabilitation process.

2.2 Norwegian national guidelines and patient pathways for treatment and rehabilitation after a stroke

The Norwegian national guidelines for treatment and rehabilitation after a stroke was created to serve the need for a national norm. The guidelines emphasize that:

> The goal of rehabilitation is to improve function/prevent loss of function and to enable a person who has had a stroke to reach their optimal physical, cognitive, emotional, social and occupational degree of independence. Rehabilitation is not solely about training and regaining function, but also about adapting to a new life situation and reintegrating into society. (The Norwegian Directorate of Health, 2017 p. 205)

The recommendations target 1) the chain of treatments, 2) assessments and treatments in the acute stage, 3) secondary prevention and 4) rehabilitation after a stroke, and are based on systematic searches and appraisal of research, clinical and user-based knowledge (The Norwegian Directorate of Health, 2017). The guidelines recommend the provision of early supported discharge (ESD) for stroke patients discharged to their homes with rehabilitation needs. They have, however, adopted a description of ESD that differs from the original concept of providing rehabilitation services in the same dose as one would receive in an inpatient facility (Norrving et al., 2018), assigning more of a coordinating role to the ESD teams, which is more suited to the geographical challenges faced in Norway. A national patient pathway for rehabilitation after stroke was released in 2019. Its aim is to promote predictability, standardisation and equality in service provision after a stroke through descriptions of assessments, acute treatments, follow-up, communication, the placement of responsibilities and a timeline (The Norwegian Directorate of Health, 2019). These routines and checklists are important to ensure quality and continuity across levels of health care. In physiotherapy, such continuity can be strengthened through interventions that accompany the patient along the rehabilitation continuum as intended in the I-CoreDIST intervention.

3 Disability after a stroke

3.1 Impairments of body functions and activity limitations after a stroke and I-CoreDIST

Impairments related to balance -including postural control, walking and upper limb function are prevalent after a stroke, commonly due to muscle weakness in the trunk and limbs, sensory loss and proprioception impairments. Adequate postural control is defined as "the organisation of multiple systems in the body to achieve both orientation and stability" (Shumway-Cook et al., 2022 p. 334). The I-CoreDIST intervention is focused around postural control as a foundation for balance, gait and upper limb function along with physical activity (Normann et al., 2019; Normann et al., 2016). The underlying understanding of trunk control in I-CoreDIST is based on Kibler and colleges' (2006) definition of core stability as "The ability to control the position and motion of the trunk over the pelvis and leg to allow optimum production, transfer and control of force and motion to the terminal segment in integrated kinetic chain activities" (p. 190). Within this definition lies the view of core muscles as all muscle in the trunk and those attached to the trunk, thus including muscles attached to the shoulder and pelvic girdle.

All movements involve some degree of displacement of centre of mass and therefore movement always starts, proceeds and end with postural adjustments. These postural adjustments are effectuated through feed-forward (anticipatory postural adjustments) and feedback (compensatory postural adjustments) mechanisms in the neuromuscular systems. Trunk muscles are central in producing such adjustments (Chen et al., 2015; Horak, 2006). Anticipatory postural adjustments are proactive postural corrections in trunk and leg muscles that prepare us for upcoming balance challenges or displacements. Compensatory adjustments are balance corrections made in response to perturbations (Horak, 2006). Trunk muscles have bilateral innervation (Brodal, 2010), and a unilateral stroke may as such result in bilateral trunk weakness and thus impaired mechanisms for both anticipatory and compensatory balance adjustments bilaterally (Curuk et al., 2019). Trunk control is often reduced after a stroke, it is associated with poor functional mobility, reduced independence in activities of daily living and an increased risk of falls (Cabrera-Martos et al., 2020; Isho & Usuda, 2015; Van Criekinge et al., 2019; Verheyden et al., 2006). Positive correlations between trunk control, core muscle strength and balance confidence have been established in chronic strokes (Karthikbabu & Verheyden, 2021). Balance is defined as “the ability to control the body’s centre of mass within the base of support” (Shumway-Cook et al., 2022) and depends on the integration of sensory inputs from the visual, vestibular and somatosensory systems, used to control anticipatory and reactive motor output to correct postural disturbances. Poor balance increases fall risk and poor balance confidence can lead to reduced levels of physical activity and participation (Hellström et al., 2003; Ng, 2011). Walking presupposes the activation of muscles in lower limbs, trunk, and upper limbs in a certain spatiotemporal pattern to ensure appropriate joint positions to support and advance the body weight in different phases of gait cycles (Li et al., 2018). Walking dysfunctions occur in the majority of people who have had a stroke and are due to the complex neuromuscular control required for walking characterized by a wide spectrum of abnormalities (Li et al., 2018). Gait problems, that are often observed and targeted in therapy, are asymmetry, reduced walking speed, reduced stride length, muscle weakness and spasticity (Li et al., 2018). Levels of physical activity and fitness after a stroke are low with regards to quantity, duration and intensity, despite studies generally representing high-functioning participants (Field et al., 2013; Saunders et al., 2020). The foundation of the I-CoreDIST intervention is to optimize function by addressing the prerequisites for postural control, balance and gait (Normann et al., 2016). It offers a comprehensive and science-based approach to rehabilitation reinforcing the importance of individualisation and an awareness of the need to promote intensity and an increase in levels physical activity.

3.2 Participation restrictions after a stroke

Low participation and inactivity are known challenges in the stroke population and are predictive of poor outcomes in rehabilitation (Elloker & Rhoda, 2018; Jones et al., 2020; Paolucci et al., 2012). Participation has many definitions, in the International Classification of Functioning, Disability and Health (ICF) framework participation is defined as "involvement in a life situation" (World Health Organization, 2013 p. 8). However, in the context of this mixed method study we applied the perspective provided by Mallinson and Hammel (2010), stating that "participation necessarily occurs at the intersection of what a person can do, has the affordances to do, and is not prevented from doing by the world in which he or she lives and seek to participate" (p. 30). Eriksson et al. (2013) reported that a third of mild stroke sufferers were unable to return to full participation in their communities following their strokes. People who have had strokes have reported personal, environmental and stroke-related factors as potential barriers to resuming participation in their life roles after a stroke (Ezekiel et al., 2019), indicating a multifactorial nature of participation. A knowledge gap exists regarding the underlying factors restricting or promoting such participation. Several authors have pointed to the need to address environmental and psychosocial factors, including support, relationships, the physical environment and access to services, when investigating participation restriction (Della Vecchia et al., 2021; Luker et al., 2015). Investigations into patient experiences link alterations in self-perception, identity, loss of self and altered roles after a stroke to changes in participation (Anderson & Whitfield, 2013; Hole et al., 2014; Roenn-Smidt et al., 2021). There is a need for studies that aim to determine the optimal rehabilitation strategy for improving participation (Obembe & Eng, 2016). The understanding of the complexity of post-stroke participation can be enhanced through investigating lived first-hand experiences. In addition, extending the theoretical foundations of the underlying connections between the person, their actions and the environment may inform the understanding of connections between post stroke impairment and participation restrictions.

3.3 HRQOL

HRQOL refers to how well a person functions in their life and to their perceived wellbeing in terms of physical, mental, and social domains of health (Hays & Reeve, 2008), aspects which are commonly reduced after a stroke (Xie et al., 2006). Being female, of an older age and having suffered higher stroke severity predict lower levels of HRQOL after a stroke (Phan et al., 2019). Nevertheless, even in people with mild disabilities or who make a complete physical recovery, fatigue and psychological issues can hugely affect their quality of life (Balakrishnan et al., 2017). Assessment methods for HRQOL are often designed to elicit the value people place on a particular health state. Interview-based studies often reveal a wider range of categories within health domains that are important to patients than questionnaire-based patient reported outcome measures (PROM's) (J. Gray et al., 2014) and they may serve as a valuable supplement to standardised measures of outcomes. The investigation of HRQOL through PROMS and interviews will add value to clinical trials and may illuminate new aspects of the relationship between impairments and HRQOL.

4 Restoration of motor function after stroke

4.1 Plasticity

Neuroplasticity refers to the functional and structural changes in the brain that occur during development, interaction with the environment, learning, ageing and in response to trauma (Sampaio-Baptista et al., 2018). After a stroke, complex spontaneous and learning-dependent processes form the basis for functional recovery (Xing & Bai, 2020). Improvements in motor performance occur through recovery and/or compensation (Cramer & Nudo, 2010; Langhorne et al., 2011). Motor recovery refers to the reacquisition of motor skills and motor compensation concerns the adaptations of movements to perform a task in a manner different from before the injury (Cramer & Nudo, 2010). Neural repair is required for recovery, changes that for the motor system are best measured with kinematics (Bernhardt, Hayward, et al., 2017). Levin et al. (2009) have suggested a definition of motor recovery and motor compensation that links the neural strategies to the levels of the motor system within the ICF classification (Table 1). On the neuronal level, early, spontaneous recovery and the brain's ability to salvage and repair the penumbra occur through the restoration of blood flow, the reduction of oedema or the recovery of neural shock (Grefkes & Fink, 2020; Sampaio-Baptista et al., 2018). Shortly after a stroke, plasticity-enhancing mechanisms that lead to dendritic growth, axonal sprouting and the formation of new synapses are in place and support behavioural recovery (Hordacre et al., 2021; Selzer, 2014). Based on current knowledge there seems to be a particularly favourable window of opportunity during the first three to six months after a stroke (Bernhardt, Hayward, et al., 2017; Dobkin & Carmichael, 2016) (Figure 1). Rehabilitation and exercise are representative of learning-dependent processes and are along with enriched environments strong drivers of neural plasticity and reorganisation after stroke (Cramer & Nudo, 2010; Grefkes & Fink, 2020; Hordacre et al., 2021; McDonald et al., 2018; Xing & Bai, 2020).

Level	**Recovery**	**Compensation**
ICF: Health Condition (neuronal)	*Restoring function in neural tissue that was initially lost after injury*. May be seen as reactivation in brain areas previously inactivated by the circulatory event. Although this is not expected to occur in the area of the primary brain lesion, it may occur in areas surrounding the lesion (penumbra) and in the diaschisis.	*Neural tissue acquires a function that it did not have prior to injury.* May be seen as activation in alternative brain areas not normally observed in nondisabled individuals.
ICF: Body Functions/Structure (performance)	*Restoring the ability to perform a movement in the same manner as it was performed before injury.* This may occur through the reappearance of premorbid movement patterns during task accomplishment (voluntary joint range of motion, temporal and spatial inter-joint coordination, etc.).	*Performing an old movement in a new manner.* May be seen as the appearance of alternative movement patterns (i.e. recruitment of additional or different degrees of freedom, changes in muscle activation patterns, such as increased agonist/antagonist coactivation, delays in timing between movements of adjacent joints, etc.) during the accomplishment of a task.
ICF: Activity (functional)	*Successful task accomplishment using limbs or end effectors typically used by nondisabled individuals.*	*Successful task accomplishment using alternate limbs or end effectors.* For example, opening a package of chips using 1 hand and the mouth instead of 2 hands

Table 1: Definitions of motor recovery and motor compensation at three different levels of the motor system (Levin et al., 2009, p. 316)

In addition, plastic muscular changes, likely caused by structural changes in the spinal motor neuron and its muscle fibres, contribute to the loss of motor control (Vieira et al., 2019). Rehabilitation also aims to counteract maladaptive neuro-/muscular- plastic changes such as those caused by “learned non-use” or “learned bad-use”. These terms refer to situations where a patient will avoid performing a movement because it is too difficult or adopt unfortunate compensatory movement patterns that will cause the motor representation of those movements in the brain to degrade (Levin & Piscitelli, 2022; Raghavan, 2015). It is important to be aware that much of the current knowledge of neural plasticity and repair is largely based on animal studies and that there is a large amount of variability in the results (Dimyan & Cohen, 2011; Sampaio-Baptista et al., 2018; Xing & Bai, 2020).

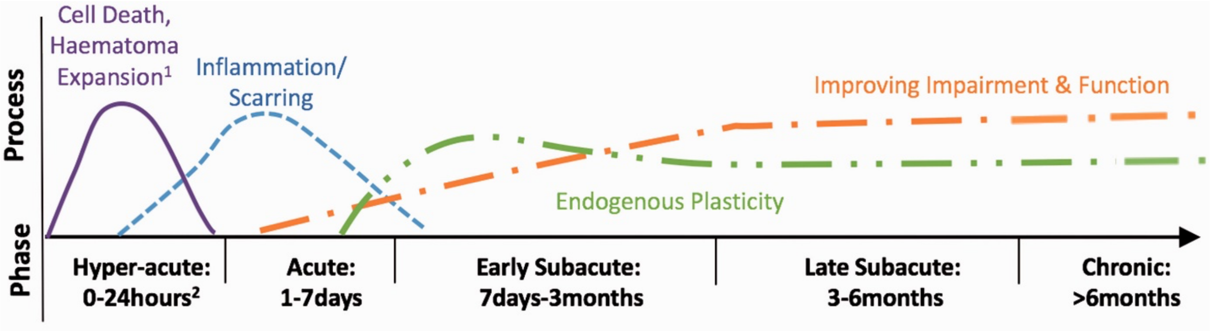


Figure 1: Framework that encapsulates definitions of critical timepoints post stroke linked to the currently known biology of recovery (Bernhardt et al., 2017; Dobkin & Carmichael, 2016)

While findings from such studies do not directly translate to humans, fundamental principles can be used to guide rehabilitation (Levin & Demers, 2020). Therefore, understanding and identifying structural changes associated with improved recovery and greater functional gains could inform tailored rehabilitation approaches and novel interventions to optimally boost adaptive brain and muscular changes.

4.2 Motor learning and motor control

Motor learning refers to the learning of new ways of sensing and moving, described as a process that strengthens the relationship between perception, cognition and action consistent with task and environmental constraints (Levin & Demers, 2020; Shumway-Cook et al., 2022). Motor learning is also the mechanism by which skills and movements are relearned after a stroke, within which the understanding of how movement is controlled is central. Motor control describes how the central nervous system finds a set of potential solutions, using the available degrees of freedom to produce a given movement task (Levin & Demers, 2020). This understanding of motor control builds on the principle that normal movement is abundant movement, referring to the many ways in which kinematic degrees of freedom can be combined to accomplish a particular task (Latash, 2012a). Adaptability in movement strategies is necessary as task demands vary for example, reaching for a glass on a table in front of oneself is different from reaching for a glass on a top shelf. This understanding of motor control and learning builds on dynamic systems theory and promotes a recognition that movement emerges from the interaction of the individual, the task and the environment (Shumway-Cook et al., 2022). In post-stroke rehabilitation, the physiotherapists' role in terms of motor learning is to optimise the foundations for movement such as the somatosensory function, patterns of muscle activation and alignment. In doing so, the aim is to enable the patient to control the degrees of freedom in a given movement/function through individualising treatment and supporting the individual (i.e. hands-on facilitation, choice of starting position) and the adaptation of the task (i.e. the length of reaching or height of stepping) or the environment (i.e. support to maintain one's position or rising from a high vs a low seat) to allow for mastery and gradual progression. New interventions need to incorporate principles of individualization, task and environmental adaptations to optimise motor learning.

5 Physiotherapy in stroke rehabilitation

Physiotherapy involves the interaction between physical therapists, patients/clients, other health professionals, families, care givers and communities in a process where movement potential is examined/assessed and goals are agreed upon, using knowledge and skills unique to physical therapists (World Confederation for Physiotherapy, 2019). Physiotherapy interventions in stroke rehabilitation commonly consist of ambulatory and balance training, transfers, and exercises of movement control in various positions (De Wit et al., 2006). Due to the heterogeneity of impairments after a stroke, a thorough assessment and clinical reasoning skills are key to providing targeted, individualised physiotherapy. Physiotherapy practice should be evidence-based to promote effective services (figure 2). Evidence-based practice (EBP) entails the integration of the best available research, clinical expertise and patient values/choices (Scurlock-Evans et al., 2014). In Norway, guidelines for stroke are heavily influenced by research evidence. This research is, however, in many cases inconclusive, hence the guidelines provide only generalised recommendations on balance, gait, task-related practice and intensity (The Norwegian Directorate of Health, 2017). Decisions regarding the specific content of training are largely based on the physiotherapist's clinical expertise. Knowledge of what actually constitutes usual care in post-stroke physiotherapy in Norway is scarce, and user experiences of physiotherapy after stroke, including assessment, goal setting, the content of treatment, individualisation and decision-making, are needed. The implementation of I-CoreDIST includes training to strengthen the physiotherapists' skills in terms of assessment, clinical reasoning and individualisation, as well as an intervention based upon available knowledge from neuroscience and clinical research.

Figure 2: Evidence based practice (https://www.csp.org.uk/professional-clinical/clinical-evidence/evidence-based-practice/what-it)

5.1 Evidence base for physiotherapy interventions

In terms of the evidence base, it is not clear which aspects of physiotherapy, such as content, session frequency or length that result in improved outcomes (Dong et al., 2022). In research, physiotherapy interventions for stroke are grossly divided into those directed towards mobility/gait, balance or upper limb recovery. In daily function, and in physiotherapy, such skills are needed in combination, and are difficult to distinguish from each other. There are vast amounts of research on particular approaches to post-stroke training, and several systematic reviews and meta-analyses focus on specific approaches, such as constraint-induced movement therapy, treadmill training, aerobic exercise and motor imagery, along with more novel approaches such as virtual reality, robotics and transcranial direct current stimulation (Bruni et al., 2018; Calabrò et al., 2021; Chow et al., 2022; Marques-Sule et al., 2021; Mehrholz et al., 2020; Zhou et al., 2021). A complete review of the evidence base for these interventions is beyond the scope of this thesis. In fact, no global systematic appraisal of research on physiotherapy for stroke has been performed since that by Pollock et al. in 2014. The heterogeneity of physiotherapy interventions and the weak methodological quality of the studies often limits the interpretation of and confidence in the findings from systematic reviews and meta-analyses (Arienti et al., 2019; Hugues et al., 2019). There is a need for larger clinical trials with sufficient statistical power (Dong et al., 2022). In the following, a brief overview of the recommendations from selected guidelines and the results of systematic searches[2] concerning the main areas for physiotherapy input in stroke rehabilitation relevant for I-CoreDIST and the outcome measures chosen to assess its effect (trunk training, balance and

---

[2] Searches in Ovid's Medline, Ovid's Embase, Ovid's AMED, PubMed and Pedro. Search terms: «stroke» AND «rehabilitation» AND («physiotherapy» OR «physical therapy»). This search combination was separately combined with AND «trunk training» / AND «core training» / AND «balance» / AND «walking» / AND «physical activity». The latest search was conducted on the second of september 2022

gait training, physical activity and HRQOL) have be reviewed. Upper limb training has been omitted as it is not specifically measured in the investigation of I-CoreDIST.

5.1.1 Trunk training

Several guidelines recommend that people with impaired sitting balance after stroke should receive trunk training exercises (Teasell et al., 2020; The Intercollegiate Stroke Working Party, 2016). This is based on evidence from systematic reviews and meta-analysis demonstrating that trunk training can improve trunk control, sitting and standing balance and mobility (Gamble et al., 2021; Van Criekinge et al., 2019). Studies of trunk control that incorporate kinematic measures are called for (Gamble et al., 2021).

5.1.2 Balance

Guidelines recommend evaluation to identify specific balance limitations. Such evaluations should guide the selection and tailoring of balance-specific interventions. Therapists should consider both voluntary and reactive balance control within their assessments (Winstein et al., 2016) . Several guidelines and reviews recommend progressively challenging, functional and task specific balance training. If lower limb weakness is present strengthening exercises should be implemented and somatosensory stimulation of the foot seems beneficial (Arienti et al., 2019; Aries et al., 2022; Pollock et al., 2014; Teasell et al., 2020; The Intercollegiate Stroke Working Party, 2016; Verbeek et al., 2014; Winstein et al., 2016). No specific balance intervention has been demonstrated to be superior, nor is the optimal timing clear (Winstein et al., 2016). Inconsistent effects of training on balance outcomes are reported in systematic reviews (Arienti et al., 2019; Duijnhoven et al., 2016; Hugues et al., 2019), but physiotherapy is reported to have beneficial overall effects on balance and postural stability (Gamble et al., 2021).

5.1.3 Walking

People with limited ability to walk after stroke should be assessed by a physiotherapist with experience in neurological rehabilitation (The Intercollegiate Stroke Working Party, 2016). Gait-related activities include mobility during rising to stand, sitting down, stair climbing, turning, transferring, using a wheelchair and walking. These aim to optimise alignment and interaction between body joint positions, improve patterns of muscle activation and adaptation to the base of support (Aries et al., 2022; Li et al., 2018). Recommendations include walking with cardiorespiratory and/or muscle strength components (Mehrholz et al., 2017; Teasell et al., 2020; The Intercollegiate Stroke Working Party, 2016; The Norwegian Directorate of Health, 2017; Verbeek et al., 2014; Wevers et al., 2009). Treadmill training, with or without body weight support, may increasing the repetitive practice and intensity of gait training, but the effects are unclear. Walking speed and endurance may improve slightly in the short term, mostly for people who are able to walk (Mehrholz et al., 2017). The long-term effects and carry-over to participation are unclear (Nascimento et al., 2021).

5.1.4 Physical activity

Levels of physical activity and physical fitness are low after a stroke (Saunders et al., 2020). Specific guidelines for the stroke population recommend 20-60 minutes of aerobic activity 2-3 times per week (Billinger et al., 2014). Interventions aimed at reducing sedentary time have mostly been unsuccessful (Saunders et al., 2021). High-intensity training is beneficial to improve cardiovascular fitness and mobility post stroke (Luo et al., 2020; Wiener et al., 2019), and there is sufficient evidence regarding safety and effect to incorporate cardiorespiratory and mixed (cardiorespiratory and resistance) training into post-stroke rehabilitation (Saunders et al., 2020). In I-CoreDIST the complexity of post-stroke impairment is recognised and exercises aimed at improve postural control, balance and mobility in a range of starting positions are incorporated. In the delivery of the intervention, physiotherapists are encouraged to adjust the pace and repetitions so that the patients' heart rate is elevated.

5.2 Clinical practice, complexity, relations and roles

"Physiotherapy is founded on a view of health that is specific to the profession, and on its mission of promoting health through movement" (Westerdahl, 2013 p. 1). It is concerned with identifying movement potential and optimising quality of life within the realms of promotion, prevention, treatment and rehabilitation (Westerdahl, 2013). Guidelines for post-stroke rehabilitation state that patients should participate in training that is meaningful, engaging, progressively adaptive, intensive, task–specific and goal-oriented (Teasell et al., 2020; Winstein et al., 2016). The term "engage" is a multi-dimensional construct that incorporates the roles of both the patient and the clinician. In the context of healthcare and rehabilitation Bright et al (2015), defines engagement as a "a co-constructed process, incorporating a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare" (p. 650). This view places the responsibility of creating engagement on the patient–physiotherapist dyad. The physiotherapist plays an important role in terms of continuity and in the patient's empowerment process through transferring their knowledge and building self-efficacy (Solbakken et al., 2022). Clinical practice is complex, and the therapeutic relationship has been suggested to influence the process of engagement within stroke rehabilitation, as has individualisation in rehabilitation, patient-centred practice and education and feedback in training (MacDonald et al., 2013). There is a need for more knowledge on what constitutes meaning and engagement with regard to the patients' and for investigations into the interaction that constructs the patient–therapist dyad. To generate such insight, we need theoretical frameworks that capture bodily, environmental and interactional aspects.

6 Theoretical perspectives

Theory offers interpretive lenses through which both quantitative and qualitative empirical observations can be interpreted, often used in qualitative research to move beyond descriptions towards explanations of phenomena studied (Cresswell & Poth, 2018; Malterud, 2015). In this study, both objective measures of effect and investigations into subjective experiences are utilised. The ICF and enactive theory form the theoretical frameworks for this study. They serve the dual purpose of conceptualising the study and of providing an extended vocabulary for integration and communication of results. The ICF is a classification of health and health-related domains and a framework for describing and measuring health and disability (World Health Organization, 2001). In the ICF the impact of personal factors and the environment upon disability and functioning is acknowledged. However, its biomedical construct of the body with little focus on subjectivity or consciousness is a restricting factor in identifying what constitutes meaning and engagement. Introducing a view of the body that challenges the more traditional understanding may serve as a gateway to an extended view of disability, recovery and interactions in health care. With this in mind enactive theory complements the ICF. Enactive theory is rooted in phenomenology, a key feature is the understanding of the body as the centre of expression and experience (body-as-subject) and simultaneously a biological organism (body-as-object) (Merleau-Ponty, 2008). It has strong links to dynamic systems theories, concerning the self-organisation phenomena of complex systems (Thompson, 2007). These are central to current theories on motor control and how movement emerges through complex interaction between the individual, the task and the environment (Shumway-Cook et al., 2022). Another central feature of enactive theory is the notion of embodied cognition; that cognition emerges from or is constituted by sensorimotor activity (Thompson, 2007). These features make enactive theory well suited to both the interpretation of first-person experiences and in relation to the embodied nature of physiotherapy practice.

6.1 International Classification of Functioning, Disability and Health (ICF).

As a theoretical model, the aim of the ICF framework and terminology is to recognise disability as a complex phenomenon, and to provide a common language for the description of health and health-related states aiming to aid multidisciplinary communication and the detection of unmet needs (World Health Organization, 2001). It conceptualises a person's level of functioning on three levels (Figure 3): 1) their *health conditions* as classified by the International Classification of Diseases, 2) their *functions and impairments*, where *functioning* is an umbrella term for: Body structures (anatomical parts of the body), body functions (physiological functions of body systems, such as range of motion, muscle strength), activity (the execution of a task or action) and participation (defined as involvement in a life situation). *Disability* is the umbrella term for *Impairment* (problems in body function or structure causing loss and difficulties in the execution of activities) termed activity limitations and participation restrictions (referring to problems one may experience in involvement in life situations). 3) *Environmental and personal factors*.

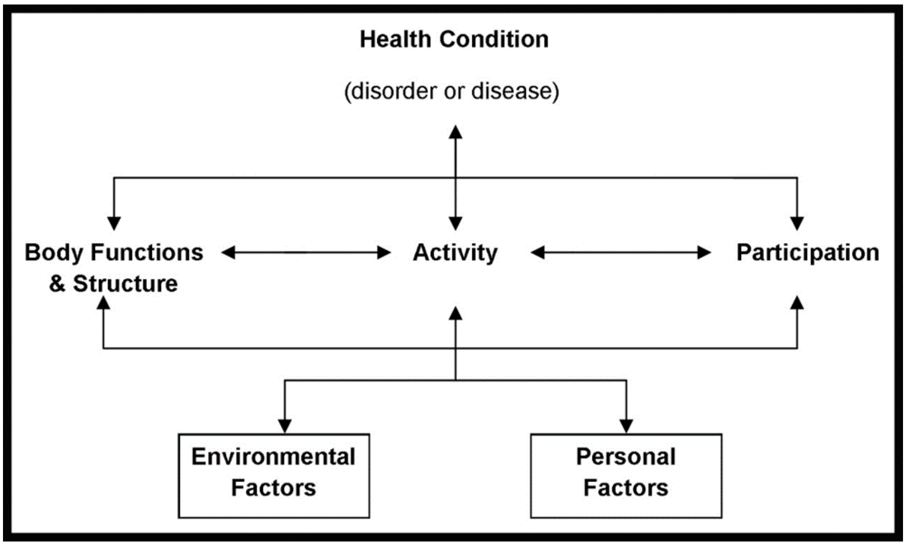


Figure 3: The ICF framework, model of functioning and disability (World Health Organization, 2001)

Both functioning and disability are the result of a dynamic interaction between contextual factors (environmental and personal) and the health condition (World Health Organization, 2001). In clinical practice this framework is highly useful in promoting a holistic view during the development of individualised rehabilitation plans (Lexell & Brogardh, 2015) and in creating awareness of the fluctuation between identification and treatment of functional problems within activity and participation domains and their underlying causes on a body function level (Shumway-Cook et al., 2022). In research in general, and this study specifically, the ICF framework is valuable in creating awareness of the classification of outcomes and choosing outcomes broadly on the spectrums of body structure/function, activity and participation levels.

6.2 Enactive theory

Enactive theory enables enrichment in terms of the exploration of how the bodily changes following a stroke may become pervasive in all areas of life instead of merely being pathological changes in the brain with consequences for motor and sensory function (Fuchs & De Jaegher, 2009). The enactive approach is constituted by five closely related concepts: 1) *autonomy,* 2) *sense-making,* 3) *embodiment,* 4) *emergence and* 5) *experience* (De Jaegher & Di Paolo, 2007) .

The concept of *autonomy* refers to how a living system is composed of several processes that actively generate and sustain an identity under precarious conditions (De Jaegher & Di Paolo, 2007, p. 487). Autonomy can emerge and generate identities at different levels, from the autonomy of the cell to the autonomy of behaviour and from of inter-subjective interaction to that of social and political systems (Barandiaran, 2017; De Jaegher et al., 2016). *Sense-making* is the active concept of participation in the creation and appreciation of meaning. It extends into the social domain, termed participatory sense-making, and is described as the process of generating and transforming meaning in the interplay between interacting individuals and the interaction process itself (Fuchs & De Jaegher, 2009). *Embodiment* refers to how the body is viewed as the centre of identity, inseparable from sensory experience and perception and how movements are the sense-maker's tools of cognition. *Emergence* describes the formation of a novel property or process out of the interaction between existing processes or events. *Experience* is intertwined with being alive and enacting in a meaningful world (De Jaegher & Di Paolo, 2007).

From an enactive point of view, the construction of meaning will always involve the body-as-a-subject in interaction with the surroundings and others. Paralysis, sensory loss or cognitive impairments following a stroke change a person's orientation and possibility for action and, thus also their perception and meaning. On this basis, one can assume that any person that has suffered a stroke resulting in bodily changes experiences themselves and the world differently than before the stroke. This will, in turn, affect their interaction with others (De Jaegher & Di Paolo, 2007; Fuchs & De Jaegher, 2009). The idea that both cognition and interaction are embodied is highly interesting in relation to investigation into experiences of and sense-making in physiotherapy.

The rules and practices of social interactions (the face-to-face encounters of everyday life) are highly conventionalised and rooted in strong social norms (De Jaegher et al., 2016). In the context of health care and the interaction between a patient and health professionals, these social norms contain a tension between paternalism and autonomy. Paternalism feature attitudes of overprotection and decision-making in another person's best interest, and autonomy contain person-centred features emphasising self-determination and self-governance (Fernandez-Ballesteros et al., 2019). In enactive theory, such patterns, where people act together according to, for example, cultural patterns, societal norms, roles or institutions, are termed coordinated patterns of behaviour (De Jaegher et al., 2016). Fernandez-Ballesteros et al. (2019) propose a "professionally driven best interest compromise model", acknowledging that paternalism and autonomy are both present in a health care context. These concepts are useful in understanding the driving forces of interactions and patient participation at the different levels of health care encountered by patients during post-stroke rehabilitation.

The common ground for the ICF and enactive theory is the appreciation of the context/environment and personal factors in experience and interaction, thus endorsing a holistic view of functioning, disability and rehabilitation. While the language of the ICF is widely recognised in health care, enactive theory provides a subjective dimension, which critics believe the ICF framework is lacking (Ueda & Okawa, 2003). Enactive theory promotes a view of the body, the brain and the environment as a unity, rather than merely connected concepts. These frameworks seem useful in a comprehensive evaluation of participation in rehabilitation, including experiences with and effects of physiotherapy.

7 Aims and research questions

The aim of this mixed methods study is to contribute to the development of new knowledge of the effects of physiotherapy and user experiences from the rehabilitation trajectory, particularly focusing on participation. Through the integration of quantitative and qualitative data I have investigated aspects of rehabilitation tied to bodily function, activity and participation from both the patient perspective and based on the utilisation of standardised measurements.

The overall research question is as follows:

What are the possible benefits and challenges regarding taking part in a comprehensive individualized physiotherapy intervention (I-CoreDIST) and usual care physiotherapy following an acute stroke along with patient perceptions of participation along the rehabilitation continuum?

The secondary research questions, addressed in the three papers are as follows:

Paper I: *Is physiotherapy with I-CoreDIST better at improving postural control, balance, physical activity, gait and quality of life than usual care physiotherapy when implemented during the first 12 weeks after a stroke?*

Paper II: *What are the basic environmental and personal factors that influence patient participation during the acute and subacute phases after a stroke?*

Paper III: *How do individuals with stroke experience the bodily and interactive course of physiotherapy during their recovery?*

8 Methodology and methods

The overall research question is the determinant of the methodology. In this study, the research question entails the investigation of objective measures of effect and subjective experiences of participation stroke rehabilitation and physiotherapy, which calls for the use of both qualitative and quantitative methods. We have employed a mixed-methods design that allows for the systematic integration of the results from the quantitative and qualitative parts of the study.

8.1 Theory of science

The beliefs and philosophical assumptions that we bring to our research are often applied via the use of paradigms and theories. Traditionally, qualitative and quantitative research build on different views of reality, truth and knowledge that are decisive for the methods used to investigate a phenomenon. Quantitative traditions are often described as belonging in positivist or post-positivist paradigms, seeking truth and evidence based on observable facts that are valid and reliable. Qualitative traditions are placed in constructivist or interpretivist paradigms and founded on a view that reality is subjective and that knowledge can be constructed through experience and reflection (Cresswell & Poth, 2018). Shaw et al (2010) state how “the paradigms that drive the research base for physiotherapy practice will shape the evidence available to inform clinical decisions” (p. 513). The nature of physiotherapy places it in the border zone between the natural and human sciences, its subject hard to define (Westerdahl, 2013). The implication of operating in this border zone is to exist in the divide between quantitative and qualitative research traditions and paradigms, highlighting the need to incorporate elements from both traditions when developing and evaluating new physiotherapy interventions. Cresswell & Poth (2018) argues for viewing quantitative and qualitative approaches not as polar opposites, but as representatives of different ends of a continuum. This project aim is to investigate both subjective and objective aspects of stroke rehabilitation as separate perspectives that complement each other and enrich the observations and analysis of participation and recovery after a stroke. This view calls for a paradigm that encompasses a variety of methods.

Pragmatism is the primary philosophy of mixed methods research (Johnson et al., 2007) and is, as a paradigm, described as mainly concerned with the outcomes of research and finding solutions “that work” for the problems investigated (Cresswell & Poth, 2018). Pragmatism has a philosophical underpinning that accepts that there can be one single or multiple realities (Kaushik & Walsh, 2019), thus embracing the combination of methods that have traditionally been placed in paradigms often viewed as incompatible. The nature of experience is emphasised in pragmatism, highlighting that the meanings of human actions and beliefs are found in their consequences and that the world/reality is not static. Consequently, as a research paradigm, it can encompass plural methods based upon a view that one cannot access the reality by solely using a single scientific method (Cresswell & Poth, 2018; Kaushik & Walsh, 2019). Shaw et al. (2010) argues for pragmatism as a platform for conducting mixed method research and Onwuegbuzie et al. (2009) state that this type of research should be used when “the nexus of contingencies in a situation, in relation to one’s research question(s), suggests that mixed methods research is likely to provide superior research findings and outcomes” (p.129). A pragmatic view provides a platform for the combination of quantitative and qualitative methods with different philosophical underpinnings as applied in this study.

8.2 Mixed methods

Approaching this study using a mixed method design allows for a richness in terms of the material of importance in the investigation into participation in rehabilitation and the usefulness of the I-CoreDIST intervention. The strength of the RCT, in rigorously following a firmly codified methodology in terms of providing valid and reproducible results, is also its weakness in the investigation of a complex phenomenon, as it may oversimplify the relationship between the intervention and the results (Bragstad et al., 2019). The patient’s motivation, the relationship with the therapist and whether the intervention is perceived as meaningful may have a strong impact upon recovery (Sivertsen & Normann, 2015) and, thus, also upon the results of the RCT. Rather than viewing the patient's experience, expectations and motivation as confounders in the response to an intervention, with the appropriate methods they may inform the results. Several different types of mixed methods research design exist. The differences between them are related to the aim of the research, the timing of the data collection and the importance given to each data type (Creswell & Creswell, 2018). Shorthand labels are often used in the description of mixed methods studies, and QUAN and QUAL are short for quantitative and qualitative, respectively. Upper case indicate that the method is emphasised, and lowercase letters indicate lesser emphasis. A plus sign indicates convergent, as opposed to sequential data collection, as the latter would have been indicated with an arrow.

8.3 Design

Based on the overall research question and the underlying pragmatic foundation, we chose a convergent parallel mixed method QUAN+QUAL design for this study, consisting of an RCT and an interview study. The two methods are given equal weight to signalise that their contributions inform different aspects of the research question that are of equal importance, yet QUAN is before QUAL as the RCT forms the basis from which participants in the interviews were selected. The flow of patients through the study is outlined in figure 4. Data were collected at the same time, apart from some interviews that were delayed due to the Covid-19 pandemic and undertaken after the last retest collecting quantitative data. Upon the inclusion and baseline testing of postural control, balance, gait, HRQOL and physical activity, the participants were randomised into two groups, that each received physiotherapy following the principles of I-CoreDIST or usual care for 12 weeks. The two groups received equal doses of physiotherapy, five days/week if in inpatient care or three days/week if outpatients. Each patient received a form where the content of the physiotherapy treatments was registered by the physiotherapists.

The registration form followed the patient during transfers between levels of health care. The baseline tests were repeated after 12 weeks. The interviews were carried out towards the end of the 12-week follow-up.

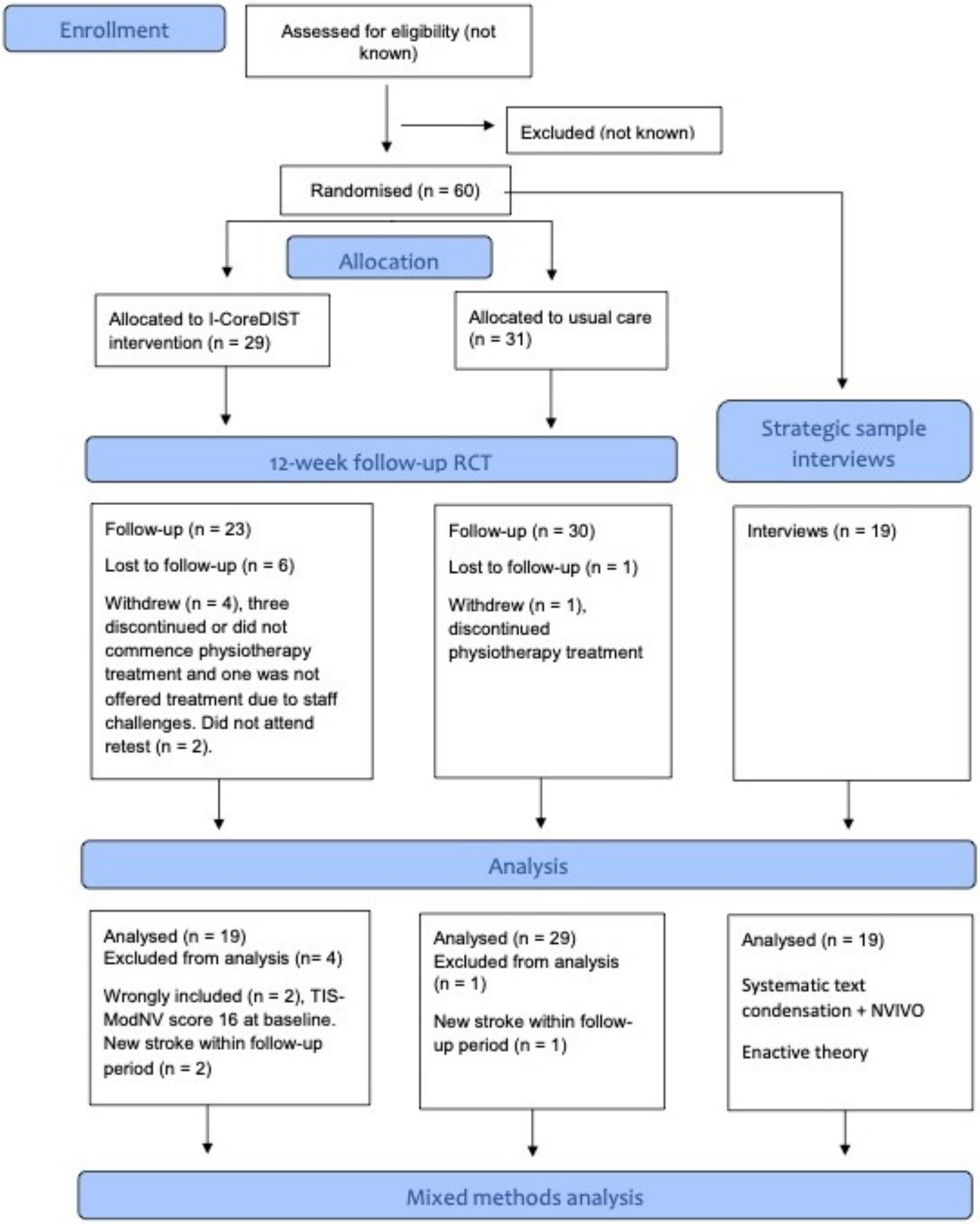


Figure 4: Flow chart of the mixed methods study

8.4 Study context

The participants in this study were recruited from the stroke units at two hospitals in Norway. These hospitals serve total populations of 83,419 (Nordland Hospital Trust, 2017) and 97,000 (Nord-Trøndelag Hospital Trust, 2021) and registered 222 and 240 admissions of patients with stroke respectively in 2021 (The Norwegian Stroke Registry, 2022). Baseline and 12-week assessments were undertaken in the hospitals by designated physiotherapists trained in the use of the relevant outcome measures. The physiotherapy treatments were carried out in eight surrounding municipalities and three in-patient rehabilitation units. Participation in this study did not affect whether the participants were discharged to inpatient or community care, nor the time of transfer from one to the other. The location of the interviews was initially in the participants’ home or a place of their choice, but as a result of the Covid-19 pandemic, after March 2020, all the interviews were carried out over the telephone and recorded on a separate digital recorder.

8.5 Recruitment and participants

A total of 60 patients were included between September 2019 and September 2021, all of whom participated in the RCT and 19 of which were strategically recruited for the interview study. Physiotherapists working at the two stroke units screened patients admitted with new strokes prior to discharge and invited eligible persons to participate. Unfortunately, due to poor compliance when filling in the screening forms, the number of patients that were screened for participation is not known. Patients were included upon the provision of written informed consent.

We chose to include participants at the point of discharge from the stroke unit. This was based on previous experiences from a preceding pilot study where recruitment and the implementation of I-CoreDIST occurred at admission to the stroke unit. We concluded that such early inclusion was not feasible for ethical and practical reasons (Normann et al., 2019). Patients were more often unable to provide informed consent, were frequently medically unstable, or were unavailable for physiotherapy treatment due to investigations and procedures.

To participate patients had to be admitted with a confirmed new stroke, be between 18 and 85 years of age, have a premorbid modified Rankin Scale (mRS) score of 0-3, be able to sit for 10 seconds at baseline testing, a Trunk Impairment Scale-modified Norwegian version (TIS-modNV) score of ≤ 15, and live in one of the eight participating municipalities. Patients were excluded if they had severe cognitive problems or previously known dementia, severe comorbid illness, or ongoing substance abuse preventing participation in rehabilitation. In addition, only patients with no severe aphasia were deemed eligible for participation in the qualitative part of the study.

To strengthen the credibility of the interview study we strategically sampled participants from both study arms, from different geographical locations and from both urban and rural areas. We also ensured that the participants differed in gender, age, stroke location and level of disability, aiming for a diverse sample, that resembled the general stroke population.

8.6 Randomisation

The participants were randomly assigned to one of two trial arms, A and B, in a 1:1 ratio using permuted blocks of random sizes. Randomisation was stratified into two groups based on functional disability at baseline defined by mRS < 4 or ≥ 4 to minimise selection bias and to preserve homogeneity between arms. Heterogeneity at the group level is a characteristic of the stroke population (Burke et al., 2015). A cut-off level of four points was chosen to ensure the equal distribution of ambulant and non-ambulant participants across the groups as we believed baseline functional disability to be a potential confounder. A digital solution, RedCap (Research Electronic Data Capture) tool hosted at the Northern Norway Regional Health Authority was used for the randomisation. The randomisation was performed by an investigator not connected to assessment or treatment of the patients, who informed the relevant physical therapists at the rehabilitation units and/or the municipalities of the group allocations. The participants and the outcome assessors were blinded to the group allocations.

8.7 Interventions, I-CoreDIST and usual care

8.7.1 I-CoreDIST

I-CoreDIST is an individualised physiotherapy approach (I) that emphasises the important relationship between dynamic trunk control (Core) and the selective task-oriented movement of the limbs (DIST). In addition, physiotherapy treatment according to I-CoreDIST principles should include high dose (D) and intensity (I); specificity, stability and somatosensory stimulation (S); teaching and training (T).

The main features of the I-CoreDIST intervention are the enhancement of dynamic trunk stability and functional movements, combined with the following:

- Optimised alignment and adaptation to the base of support and often the use of an unstable reference point for the trunk or distal body parts.
- Enhanced somatosensory integration of hands, feet and face, including the reduced influence of vision to enhance somatosensory integration.
- Proximal stability in combination with, the task-oriented movement of limbs, neck and eyes.
- Inclusion of dual (motor-motor and motor-cognitive) tasks in exercises and activities, such as indoor and outdoor walking and climbing stairs.
- Specific hands-on interactions or other adaptations to optimise neuromuscular recruitment.
- Exercises combining core activation and an increase in heart rate when: lying, sitting and walking.

In the intervention, emphasis is placed on the integration of core muscle activation into exercises that incorporate functional activities, muscle strength, active muscle lengthening, upper limb function, gait and endurance. In doing so, the aim is to strengthen the underlying prerequisites for balance and postural control, such as anticipatory postural adjustments, ankle and hip strategies.

All the physiotherapists who treated participants in the I-CoreDIST group received 45 hours of training prior to the commencement of the study, one follow-up session, and an educational package in the form of a booklet that contained 1) the theoretical rationale behind the approach, 2) assessment and clinical reasoning charts and 3) images and descriptions of all the exercises. The intervention started with an assessment to identify each patient's movement problems, supported by clinical reasoning charts (example in appendix 1). I-CoreDIST contains 44 exercises, each with five levels of difficulty and a choice of starting position to allow for individualisation. The physiotherapists were encouraged to choose exercises and adapt the level to enable the patient to experience success and preferably positive change. In addition, discussing goals, assessing and reassessing these at the beginning and end of each session were stressed. The individual exercises were assigned a colour in the I-CoreDIST booklet, indicating their main aims.

8.7.2 Usual care

The participants in the usual care group received the type of treatment that was usually offered to this patient group in that institution or municipality, yet the treatment dose was determined by participation in this study. Each individual physiotherapist made treatment choices according to the patients' specific needs and recorded these on the patient forms.

8.8 Data collection and analysis

Demographic data on age, gender, height, weight, the type and date of the stroke, the modified Rankin Scale score prior to and at admission, the Barthel Index (BI) score and the National Institute of Health Stroke Scale (NIHSS) score at admission were collected from the participants themselves and from their hospital records. In the following, the data collection and analysis for the RCT, the interview study and the mixed methods analysis will be presented separately.

8.8.1 RCT

To evaluate I-CoreDIST and usual care in a broad sense, a variety of outcome measures, aiming to cover the ICF domains of body function, activity and participation was chosen. The primary outcomes were trunk control, evaluated by the Trunk Impairment Scale -modified Norwegian Version (TIS-modNV) and levels of physical activity measured using an accelerometer, ActiGraph Wgt3X-BT (ActiGraph, LCC, Pensacola, USA). These outcomes were chosen because a main feature of I-CoreDIST training is the enhancement of trunk control, and we wished to measure this effect specifically. In addition, levels of physical activity are commonly low post stroke (Saunders et al., 2020) and are believed to be reflective of the activity limitation often experienced after a stroke. We wanted to explore whether a high dose of physiotherapy treatment aimed at the recovery of trunk control and balance would alter the prerequisites for and lead to increased levels of physical activity.

The TIS-modNV is a 0-16-point scale whereby trunk control in sitting is evaluated through the total score obtained from six items investigating dynamic sitting balance, coordination/upper trunk stability and coordination/lower trunk stability. (Gjelsvik et al., 2012). The scale has been proven reliable (Intraclass Correlation Coefficient (ICC) = 0.85) and valid for the stroke population and is sensitive to changes in trunk control (Gjelsvik et al., 2012). The scale has a floor effect as it requires the ability to sit for 10 seconds unsupported and as such, patients who have suffered more severe strokes may not be able to perform the test. The TIS-modNV does not have a ceiling effect.

The ActiGraph Wgt3X-BT is a sensitive three-axis accelerometer used to record physical activity. The participants were instructed to wear the activity monitor on a waistband for seven consecutive days after both the baseline testing and the 12-week follow-up assessment. The devices were initialised and the data were downloaded using ActiLife software (ActiGraph, LCC, Pensacola, USA). The device has been proven reliable in an adult population (Aadland & Ylvisaker, 2015) and valid (ICC = 0.70) for use in a stroke population (Campos et al., 2018).

The secondary outcomes were measures of postural control, balance, gait speed and distance and HRQOL. We used the Swedish Postural Assessment Scale for Stroke -Norwegian Version (SwePASS-NV) to measure postural control and the ability to maintain one's equilibrium during positional changes. It is a 12-item scale with increasing difficulty that measures balance in lying, sitting and standing, designed for individuals who have suffered strokes regardless of their postural competence. The SwePASS-NV is especially sensitive with regards to assessment of postural control in the first three months after stroke, and it has excellent validity ($\alpha = 0.99$, $p < 0.001$) (Benaim et al., 1999), and reliability (ICC $\geq$0.99) (Breistein et al., 2017). The scale ranges from 0 to36 points and has a ceiling, but no floor effect.

The Mini Balance Evaluation Systems Test (MiniBESTest) is a comprehensive balance measure comprising 14 items and a 0 to 28-point scale evaluating dynamic balance. The scale is divided into four subscales evaluating 1) anticipatory postural adjustments, 2) reactive postural control, 3) sensory orientation and 4) dynamic gait. It has a floor effect as the participants must be able to stand without support. The Norwegian version has shown good reliability (ICC = 0.95) and validity (Hamre et al., 2017).

Stability during quiet stance was assessed using the AMTI AccuGait Optimized^{TM} (Advanced Mechanical technology, Inc., Watertown, USA) multi-axis force plate system. The raw data gathered from a force platform are forces and moments in three planes gathered by the platform's internal coordinate system Fx, Fy, Fz, Mx, My and Mz. X, Y, and Z are orthogonal directions of the coordinate system (Z is the vertical coordinate), M represents the moment of force, F stands for force, d_X denotes the lever arm of the horizontal (shear) force F_X (d_X is measured along the z axis), and COP_X is the COP coordinate along the x axis. Similarly COP_y is the COP coordinate along the y axis. From these data Centre of Pressure (COP) coordinates can be calculated using the following formulae (Latash, 2012b): $COP_x = (M_y - F_x \text{ x } d_x)/F_z$ and. $COP_y = (M_x - F_y \text{ x } d_y)/F_z$..

In standing, the centre of mass and COP are the main outcome measures. A force platform can detect movement in the calculated COP. COP track data (distance) can be decomposed into mediolateral (ML) ($COP_{x)}$ and anteroposterior (AP) (COP_y) components for analysis. For young, healthy subjects with their eyes open COP deviations in both the AP and ML directions are in the order of 5-10 mm/ AP COP migration: 4 mm, ML COP migration: 1.8 mm. We collected data on COP displacements in cm over 30 seconds with a frequency of 50Hz, the recommended sampling frequency for measurements of balance (Stergiou, 2004), in the domains of eyes open and eyes closed. Reliability has been established for measuring COP displacements during quiet stance in the AP (ICC = 0.77) and ML (ICC = 0.74) directions in a stroke population (V. L. Gray et al., 2014).

Participants who were able to walk with or without an aid performed 1) the 10-Meter Walk Test (10MWT), measuring their walking speeds (metres/second) at their preferred and fast paces, found to be reliable (ICC=0.76) and valid for use in a stroke population (Busk et al., 2022; Cheng et al., 2021) and 2) The 2-Minute Walk Test (2MWT), measuring the total distance walked in two minutes, conducted on a 20 m walkway. We found the 2MWT to be feasible for the early subacute phase, and reliable (ICC= 0.85) for a stroke population (Kosak & Smith, 2005). For non-ambulant participants, 0 metre/sec was recorded as their baseline and/or 12-week scores.

HRQOL was reported using EQ-5D-3L and the Stroke Specific Quality of Life (SSQOL) scale. The EQ-5D-3L is a standardised health-related quality of life questionnaire developed by the EuroQol Group to provide a simple generic measure of health for clinical and economic appraisal (EuroQol Group, 1990). It comprises five dimensions recording perceived health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each has three levels of response (no problems/some or moderate problems/extreme problems).In addition it comprises a vertical, visual analogue scale from 0 to 100 where the endpoints are labelled “best imaginable health state” and “worst imaginable health state” (Rabin & de Charro, 2001). The EQ5D-3L has been proven reliable and valid for use in a stroke population (Cameron et al., 2022; Hunger et al., 2012).

The SSQOL scale assesses HRQOL specific to stroke survivors. It is a 49-item questionnaire, addressing 12 domains: self-care, vision, language, mobility, work/productivity, upper extremity function, thinking, personality, mood, family roles, social roles and energy (Williams et al., 1999). The Norwegian translation has shown excellent reliability (ICC = 0.97) and validity (Pedersen et al., 2018). The SSQOL was only administered at the 12-week retest as it was not considered appropriate in the acute stage.

8.8.2 Data analysis

The study data were collected and managed using RedCap, which is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry, 2) audit trails for tracking data manipulation and export procedures, 3) automated export procedures for seamless data downloads to common statistical packages and 4) procedures for importing data from external sources. Point scores for the TIS-modNV, SwePass-NV MiniBESTest and number of metres walked were entered into the RedCap database. The time obtained for the 10MWT fast and preferred paces were converted into metres per second before being entered into the database.

The raw data from the ActiGraph devices were converted into the categories of minutes of sedative time, minutes of light, moderate and vigorous physical activity and the number of steps using the ActiLife software.The average number of minutes per day in each category as well as the steps per day, were calculated and entered into the RedCap database.

The raw force platform data were filtered, with the aim of reducing the measurement error in both time and frequency domain. The component of the signal contributed by the actual biological movement resides at the lower end of the frequency spectrum. A filter removed frequency components above a critical cut-off value. Moments of force are used to reflect the contractions of muscles, creating postural sway. In quiet standing, the body, as an inverted pendulum, does not have a defined lowest frequency and muscle contractions produce frequencies up to about 8 Hz. Higher frequencies in the force data will create artificially high frequencies in the moments of force that cannot be explained as coming from muscle contractions. Hence, a fourth-order Butterworth (Infinite Impulse Response) filter was applied at 10 Hz. The COP data were calculated in the BalanceClinic software and exported into MatLab, where root mean square (RMS) values were calculated for the COP_x and COP_y values. RMS can be a synonym for standard deviation when it can be assumed that the input signal has a zero mean. This is recommended in the evaluation of postural sway and represents the sway amplitude (Mansfield & Inness, 2015). RMS values of COP displacements in the AP (COPy) and ML (COPx) planes were calculated using the following formulae: RMS AP=$\sqrt{\frac{1}{n}}(y_1^2 + y_2^2 + y_n^2)$, and RMS ML= $\sqrt{\frac{1}{n}}(x_1^2 + x_2^2 + x_n^2)$.

EQ-5D-3L answers were coded into digits according to the levels described in the instrument handbook (EuroQol Research Foundation, 2018): no problems = 1, some problems = 2 and extreme problems = 3. These constitute one of 243 possible unique health statuses in the form of a five-digit code (e.g. 11232). To enable further statistical analysis, we converted each health state into a single summary index value. The index values were calculated by applying a formula that attaches values to each level in each dimension. These value sets were obtained using a representative sample of the general population and the time- trade-off technique and thus, are representative of the societal perspective (Devlin et al., 2022). There is currently no available value set for Norway so we used the set from Denmark as it has been used in studies of stroke patients in Norway (Waehler et al., 2021; Wittrup-Jensen et al., 2009).

The SSQOL answers were coded into digits and entered into the database. The Norwegian translation has two response sets (a/b) that were coded as follows: could not/agree = 1, a lot of trouble/moderately agree = 2, some trouble/neither agree nor disagree = 3, a little trouble/moderately disagree = 4 and no trouble at all/strongly disagree = 5. The answers were grouped into the 12 questionnaire domains, and an index score for each domain was calculated by dividing the domain sum by the number of questions in the domain. Lastly, a total index score was calculated. Missing data were handled using person mean imputation and replaced by the domain average if one was missing in a three-question domain or two were missing in a five/six question domain. Forms that contained more than five missing items were discarded.

8.8.3 Statistical analysis

We performed an intention-to-treat (ITT) analysis. This means that all participants that have been randomised into a group in the RCT should be a part of the group analysis no matter how much of the trial is completed to reduce the risk of introducing bias and of overestimating the treatment effect (Fergusson et al., 2002). All the data were exported from the RedCap database and MatLab to SPSS for statistical analysis. Categorical variables are presented as numbers and percentages. Continuous variables are presented as mean and standard deviation (SD) or median and interquartile range (IQR) depending on the normality distribution. We fitted a regression model to the mean outcome using retest score as the dependent variable and group allocation and baseline score as the independent variables. When applying this model, the null hypothesis is no difference between groups. This is rejected at the 0.05 significance level if the 95%-confidence interval for the coefficient corresponding to the treatment variable excludes 0 (Rosenblum & van der Laan, 2009). If the data violated the assumptions for linear regression analysis, we performed a natural log transformation prior to the analysis. If we were still unable to fulfil the assumptions, we performed non-parametric tests, namely a Mann-Whitney U test, for between-group differences. Within-group differences were calculated using a paired samples t-test if the data were normally distributed and a Wilcoxon signed rank test if the premise of normal distribution was violated. The significance level was set at $p<.05$.

8.9 Interview study

8.9.1 Data collection

The interview data were collected between December 2019 and December 2020. We conducted 19 interviews that lasted between 20 and 91 minutes, and the total interview time was 840 minutes. The interviews followed a theme-based interview guide (Appendix 2) with open-ended questions. The development of the interview guide was based on a literature search and discussions between my supervisors (BN, KBA and ECA), a user representative and myself.

During these discussions, verbalising our preconceptions was particularly emphasised as my supervisors and myself have clinical experience from working in the fields of neurology and neurological rehabilitation. In addition, two of my supervisors and myself have developed the I-CoreDIST intervention. These discussions create awareness of how our experience and closeness to the field of investigations influences shape how questions are framed and interpreted (Malterud, 2017). It also highlights the need to keep an open mind to new and surprising themes during interviews. The interview-guide initiated reflections on: 1) the acute situation, 2) participation in daily tasks and activities in hospital, 3) the transfer from hospital to their home or a rehabilitation unit, 4) in-patient or out-patient rehabilitation, 5) participation in decision-making and goal-setting 6) the specific content and their experiences of physiotherapy, 7) their interaction and relationship with the physiotherapist and 8) their daily activities at home. The interview guide was assessed and slightly adjusted after the first two interviews to emphasise not only descriptions of situations but also how the informants felt about their experiences. To ensure communicative validation as recommended by Brinkmann and Kvale (2015), I asked follow-up questions, rephrased and requested details of both positive and negative experiences during the interviews. Some of the participants were aware that the interviewer was a physiotherapist, and, therefore, it was emphasised that in order to evaluate rehabilitation services, including physiotherapy, it was crucial to discuss both positive and negative experiences. This was particularly important considering my background as a physiotherapist and involvement in developing the I-CoreDIST intervention. I conducted a debrief after each interview, which revealed no negative experiences.

8.9.2 Data analysis

All the interviews were transcribed verbatim by a secretary otherwise not connected to the project and myself. The transcripts were re-checked against the audio files to ensure that they were in complete coherence. All the transcripts were imported into NVivo software, v12.6.0

(QSR International, 2019) and analysed thematically using systematic text condensation (STC) (Malterud, 2012). STC is a pragmatic procedure, inspired by Giorgi’s phenomenological analysis. The method is a systematic method of decontextualization and recontextualization consisting of four steps that allows the author to search for the essence of the phenomenon under investigation (Malterud, 2012):

1. *Overall impression*. I read each interview as a whole to gain an overall impression of the material and of the major themes that represented the participants experiences. During this stage, it was important to attempt to put my own preconceptions aside in order to remain open to new and unexpected themes. The majority of the interviews were also read by my primary supervisor, BN, and some by one of my secondary supervisors, ECA, who both, in addition to myself independently suggested preliminary themes. All the suggestions regarding the preliminary themes were discussed during workshops and we established agreement. During this process it became clear that our material covered extensive ground and was thematically divided into 1) the general course of rehabilitation and 2) specific experiences of physiotherapy treatment. We decided that the essence of the material would be better maintained if analysed separately to answer two separate research questions.

2. *Decontextualisation*. In the next step of the analysis, I identified meaning units or text fragments in the transcribed material that I considered contained information relevant to the research questions (Malterud, 2012). Based on their content, these were sorted into code groups. During this process, I continuously moved between the meaning units and the research questions to ensure that the code groups reflected the main themes in the material.

3. *Condensation.* The meaning units within each code group were sorted into subgroups. The contents of each subgroup were reduced into a condensate -a short text written in the first person and illustrated with a quote from an interview. The interpretations of the condensates were discussed by all the supervisors and the co-author. In these discussions we strived to extract the meaning in the material by asking questions like "what does this mean" or "how can we understand this".

4. *Synthesising*. The condensates were recontextualised as analytical texts in the third person, reviewed against the full transcript, and validated to ensure that the syntheses of the data reflected the original context. A category name replaced the previous code group name.

The final texts were reviewed, and the interpretations were informed by the existing literature, the authors' varied professional experience and the chosen theoretical framework, which for both the qualitative papers were different concepts within enactive theory.

8.10 Mixed methods analysis

The results from the three papers, one based on the quantitative RCT data and two based on the qualitative interview material, form the basis for the mixed methods analysis. The results were integrated through thematic analysis, which aimed to discover new categories based on common features (Onwuegbuzie et al., 2009). The analysis was performed in four steps. The first step was to extract the main findings from each paper. Keywords representing these were organised into a table. In step two, the keywords were scrutinised for common themes. Three main overlapping themes were found, and the keywords were reorganised thematically. Based on the keywords I wrote a summary for each category.

9 Results

9.1 Paper I

Effect of Innovative versus Usual Care Physical Therapy in Subacute Rehabilitation after stroke: A Multicentre Randomised Controlled Trial

In this paper we report the results from an assessor-masked RCT where we compared the effects of I-CoreDIST, with usual care physiotherapy on postural control, balance, physical activity, gait and HRQOL during the first 12 weeks after a stroke. The study included 60 participants who were randomised into I-CoreDIST (n = 29) or usual care physical therapy (n = 31) groups, received five physiotherapy sessions/week if they were inpatients or three sessions/week as outpatients. Primary outcomes: TISmodNV and activity monitoring (ActiGraph Wgt3X-BT). The secondary outcomes: SwePASS-NV, MiniBESTest, 10MWT, 2MWT, force platform measurements and EQ-5D-3L, all conducted at baseline and at 12 weeks. The SSQOL scale was only administered at 12-weeks. Linear regression and non-parametric tests were used for the statistical analysis. The content of physiotherapy sessions was registered on specific forms.

We found no significant between-group effects for the primary outcomes: TIS-modNV (p = 0,857); daily average minutes of sedative, (p = 0.662), light (p = 0.544), moderate (p=0.239) activity and steps (p = 0.288) or for the secondary outcomes at 12 weeks except for significant gains in EQ5-D-3L in the usual care group (p = 0.003). The within-group changes suggest improved postural control, balance and gait in both groups. Only the I-CoreDIST group showed significant reductions in sway amplitude during standing and only the control group achieved significant improvements in 10MWT fast pace and moderate levels of activity. Activity levels remained low throughout the study period. Drop-out rates are shown in figure 4. To conclude, there were no difference between groups, except significant gains in HRQOL in favour of the usual care group following 12 weeks with either I-CoreDIST or usual care physiotherapy.

9.2 Paper II

The precarity of patient participation – a qualitative interview study of experiences from the acute stroke and rehabilitation journey

In paper II we explored how stroke survivors perceived the transition from being an independent individual to one in need of help and if their role in rehabilitation influenced active participation. We interviewed 17 stroke survivors and analysed the data using systematic text condensation. The analysis was informed by the term *autonomy* from enactive theory.

A major finding of this study is that structures of multidisciplinary teamwork, communication and including the patient in decision-making varied between levels of health care. The culture and protocols of hospitals discouraged active patient participation, despite its high importance in early stroke rehabilitation. Patient participation changed from initially being autonomous decision-makers when the stroke hits to becoming passive receivers of treatment and care in hospital. This may have lasting consequences after discharge. Patients who were discharged from the stroke unit to their home felt unprepared, some found the transition particularly difficult as cognitive challenges and fatigue were not detected while in hospital. Yet, participatory enablement was a distinct feature of rehabilitation units and life in the community. Patients were more prepared for the transition to home after in-patient rehabilitation than following discharge from hospital. Support and progress in physiotherapy was important for motivation and many found the transition to training independently after 12 weeks difficult.

In conclusion, bodily changes, the traditional patient role and the hospital context mutually reinforce a reduction in individual autonomy and actualise how partnerships in terms of interactions with multidisciplinary professionals, partaking in decision-making and experiencing progress in training may strengthen autonomy and promote participation after a stroke.

9.3 Paper III

Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke. A qualitative study

In this paper we investigated how individuals who had suffered strokes and received either I-CoreDIST or usual care physiotherapy experienced the bodily and interactive course of physiotherapy during their recovery processes. The study was nested within an RCT (paper I) and consisted of in-depth interviews with 19 stroke survivors. The data were analysed using systematic text condensation, and the analysis was informed by enactive theory.

The experiences shared revealed that the interactions with physiotherapists were guided by perceived bodily changes and ranged from being formal/explicit to tacit/implicit. While participants had a passive role in assessments their active efforts were demanded in training. The generation of meaning and motivation in physiotherapy was closely tied to experiencing positive bodily changes and the tailoring of difficulty and intensity levels regardless of group allocation. Improvements in general fitness contributed significantly motivation during plateaus in ADL-recovery. Trust and engagement were considered important aspects of the interaction between the participants and their physiotherapists, involving both interpersonal skills and professional expertise. The experiences of participants in the intervention group and the usual care group differed predominantly with regard to the content and context of the therapy sessions and the means of measuring progress; divergences in levels of satisfaction with the treatment were less pronounced.

The embodied nature of physiotherapy practice is a source of sense-making and meaning-construction for patients after a stroke. Experiencing bodily changes and exertion from post-stroke training can facilitate sense-making, inspire commitment and a positive attitude towards physiotherapy. Experiencing progress and individualising approaches are decisive motivators.

9.4 Integration of the findings

The key findings from the three papers have been integrated and synthesized into three categories according to the description in section 8.9: 1) Transitions — enablers of and challenges for participation at the system level, 2) Structures and traditions in institutions and municipalities shape the delivery of care 3) Meaning, progress and embodiment (table 2). Framing the integrated findings in these new categories allows for wider discussions of phenomena composed of different dimensions than do each paper alone. In addition, these discussions will highlight findings that have not been thoroughly discussed previously, such as interpretations of baseline findings and registration forms.

	Key findings	New category
Paper 1 RCT	Becoming unable; interpretation of baseline scores Becoming able; 12-week scores. Sustained inactivity despite improved motor function	Transitions — enablers of and challenges for participation at the system level
	Content in physiotherapy, registration forms No between-group differences, except for EQ-5D-3L improvements in the usual care group.	Structures and traditions in institutions and municipalities shape the delivery of care
	Significant within-group changes in both groups (TISmodNV, SwePASS-NV, MiniBesTEST, 10mwt, 2mwt) Approach is partly reflected in the results (force platform and gait speed) SSQOL-scores	Meaning, progress and embodiment
Paper 2 Participation	Experiences of becoming unable. From autonomous to passive receivers of treatment and care. Transitions through levels of health care Transition from one-to-one physiotherapy to being independent in exercise is difficult	Transitions — enablers of and challenges for participation at the system level
	The organisation of multidisciplinary teamwork varies between levels of health care. Precoordinated patterns of behaviour shape interactions and the patient's involvement in decision-making Partnership in interaction is a facilitator of autonomy and participation Inactivity in institutions	Structures and traditions in institutions and municipalities shape the delivery of care
	Progress in training is important for motivation Cognitive problems and fatigue	Meaning, progress and embodiment

Paper 3 Physiotherapy	Transition from being evaluated (passive) to actively making effort in training	Transitions — enablers of and challenges for participation at the system level
	Variations regarding content of physiotherapy Variation in context of physiotherapy treatments Participants are satisfied with treatments regardless of content and context	Structures and traditions in institutions and municipalities shape the delivery of care
	Group differences regarding approach and content Exertion in training is meaningful, enhanced connection with their bodies Unified approaches to assessment, diverse approaches to treatment. Individualization and an embodied approach facilitate sense-making	Meaning, progress and embodiment

Table 2: Synthesis of findings

10 Discussion

In this section a discussion of the three new categories and the methodological considerations of the mixed methods study and its quantitative and qualitative parts will be presented.

10.1 Discussion of the integrated findings

In the following, the new categories identified will be discussed in relation to the overall research question: *What are the possible benefits and challenges regarding taking part in a comprehensive individualized physiotherapy intervention (I-CoreDIST) following an acute stroke along with patient perceptions of participation along the rehabilitation continuum?* Each category starts with a summary based on common themes from the three papers and is followed by a discussion, summarised in key challenges and benefits at the end. The first category*, transitions — enablers of and challenges for participation at the system level* will be discussed mainly in terms of factors that shape the rehabilitation continuum at the governance level. The second category, *structures and traditions in institutions and municipalities shape the delivery of care* will be discussed at the institutional level and the third category, *meaning, progress and embodiment,* will be discussed at the individual and interpersonal levels. These three layers are intended as an elucidation of the filters that shape services and patient participation after a stroke and will be illustrated in a figure following the discussions.

10.1.1 Transitions — enablers of and challenges for participation at a system level.

The integrated findings highlight that the rehabilitation continuum following a stroke is characterised by transitions on multiple levels. All three papers feature the transition from being able, to becoming unable when the stroke hits and then becoming able again during rehabilitation. This is evident in the premorbid mRS, baseline and 12-week measures of postural control, balance, gait and HRQOL. Moreover, it is also reflected in the participants' descriptions of losing and regaining functions. The experiences related to the stays in the stroke units were characterised by the ambiguity of being efficient yet rushed, while the patients were passive recipients of treatment and care. For some this institutionalisation and reduced autonomy may carry over to their everyday lives. Both I-CoreDIST and usual care physiotherapy is viewed as facilitators of the transition from being unable to becoming able due to its association with physical exercise and positive bodily changes.

Transfers between levels of health care represent a threat to continuity that evokes feelings of insecurity and a lack of predictability. Short stays in the stroke unit and discharges that are often rushed point to a discrepancy between the expected and actual levels of autonomy. Such experiences are in contrast to well-planned processes when discharged from a rehabilitation unit. In the following I will discuss how governance, that is, guidelines, policies, resources and finance influences experiences of participation in the rehabilitation continuum and services at this superior level.

10.1.1.1 Becoming unable and re-enablement — the evaluation of disability

The participants' pre-morbid mRS scores indicate low disability before their strokes (Banks & Marotta, 2007). The extent of disability and recovery is, in part, defined by the tools utilised to measure outcome. In the Norwegian national patient pathway, the combination of the mRS and BI-scores forms an algorithm that is weighted heavily in the assessment of rehabilitation needs along with the patients' motivation and ability to partake in intensive therapy (The Norwegian Directorate of Health, 2019). In this study, the classification of NIHSS scores[3] (Kogan et al., 2020) revealed that the usual care group had suffered mild strokes, and the intervention group came under the category of moderate strokes The BI scores[4], classified into levels of dependency (Shah et al., 1989), indicate that both groups were at moderate levels at baseline.

---

[3] NIHSS: no stroke symptoms, 0; minor stroke, 1 - 4; moderate stroke, 5 - 15; moderate to severe stroke, 16 - 20; severe stroke 21 - 42

[4] BI: Total dependency, 0 - 20; severe dependency, 21 - 60: moderate dependency, 61 - 90; slight dependency, 91 - 99; independent, 100

Our data show discrepancies between the participants experienced loss of function, such as being unable to walk or talk, disabling levels of fatigue and personality changes and those measured by the NIHSS and BI at baseline, illustrating that these tools captured limited aspects of disability. The integrated findings highlight how the incorporation of outcomes that capture first-hand experiences of disability, such as those based on interviews or PROMS, as an addition to standard assessments creates a more nuanced view of a patient's health status and may potentially improve the services offered.

The patients descriptions of reduced functioning are supported by specific baseline assessments of postural control, balance and gait speed (TIS-modNV, SwePASS-NV, MiniBesTEST, 10MWT and 2MWT) revealing average scores below the available normative values for older adults (Benaim et al., 1999; Bohannon, 1997; Lee et al., 2018) and within the "risk of falls" category (Kauhanen et al., 2000; Persson et al., 2011). Today's practice of leaning heavily upon generalised assessments of body functions and activity may lead to important aspects of disability, such as reduced postural control or balance problems, being missed. These evaluations have a substantial impact upon the rehabilitation continuum. A comprehensive assessment of functioning and rehabilitation in the early phase would benefit from including all the ICF model's domains of body functions, activity and participation, in the context of environmental and personal factors. In addition, such assessments ought to be specific to common impairments after a stroke, such as prerequisites for balance and mobility and include the evaluation of possibilities for change.

In our study, the inactivity experienced early after stroke sustains the sense of being unable through inactivity and the lack of involvement in decision-making, which affect autonomy. This is in line with findings of others (Mattlage et al., 2015; Sjoholm et al., 2014) and is in contrast to guidelines for early rehabilitation and current knowledge of neuroplasticity. Laws, policies and guidelines make hospitals, with their protocol- and rule-based system, strong regulators of behaviour (De Jaegher, 2013). A stroke unit without a focus on rehabilitation has no certain effects and this study points to the fact that there is little room for multidisciplinary rehabilitation as outlined in the definition in the Norwegian guidelines (The Norwegian Directorate of Health, 2017). Is traditional rehabilitation within the scope of a modern stroke unit? I argue that the combination of several factors, including; reduced length of stay placed upon hospitals as part of the Coordination reform (SSB 2017), financial hardship in the hospital sector, excellent developments in acute treatment and the discovery of potential harmful effects of very early mobilization (<24h) after a stroke (Langhorne et al., 2017), leave little time for rehabilitation in the form of traditional therapy. Discussions regarding multidisciplinary rehabilitation in the stroke unit need to consider that spontaneous recovery and endogenous plasticity processes are in place within the first seven days after a stroke (Bernhardt, Godecke, et al., 2017) and should be supported by addressing motor control/recovery along with physical activity. In addition, today's practice of generalised assessments and levels of inactivity limit opportunities for making just assessments of a patient's motivation and ability regarding taking part in intensive therapy. This provides an example of how politics and policy on the one hand and guidelines for practice and knowledge from research on the other hand are guiding clinical practice in different directions.

The commencement of physiotherapy after discharge from hospital as outlined in the RCT entail more defined expectations towards the patient's active participation in the process of becoming able, regardless of discharge destination. There was no statistically significant difference between groups in terms of effects except for significant gains in EQ-5D-3L in the usual care group at 12 weeks. There were also fewer dropouts in the usual care group indicating high compliance with treatment. There were significant between-group improvements in baseline-scores measured at 12 weeks will be discussed in detail in section 10.1.3. However, on an overall level the significant improvements in both the I-CoreDIST and usual care groups in terms of postural control, balance and gait align with the participants descriptions of becoming able during the 12-week follow up period.

10.1.1.2 Transfers

The perceptions of rushed discharges found in our material, must be observed in relation to the short stays in the stroke unit. Both units in our study had average stays (three and five days) below the national average (The Norwegian Stroke Registry, 2022). In the wake of the Coordination reform, aiming to reduce length of stay in hospitals, hospital departments issue daily fines to municipalities if unable to accept patients by the date they are declared ready for (Haukelien et al., 2015; The Ministry of Health and Care Services, 2011a). These changes in practice counteract seamless transfers between levels of health care. While Norway’s health care system receives top rankings internationally, its scores are low regarding the coordination of services (The Commonwealth Fund, 2017). The implementation of the RCT identified how missed referrals were mainly picked up due to parallel communication related to patients’ participation in this research project and not by the patients or the discharging hospitals. Patients find themselves at a vulnerable stage in their illness trajectory following the overwhelming event of a stroke when their bodily perceptions, participation in everyday life and sense of self undergo profound changes (Arntzen, Hamran, et al., 2015), and advocating for themselves may be difficult. The participants’ experiences of discharge from hospital to the municipality are in contrasted to well-planned processes when being discharged from a rehabilitation unit. At this point in time, they were somewhat further down the timeline of recovery and negotiating their new self-identities. Home visits together with health professionals made them feel safer about returning home. Pallesen (2014) argues that it is valuable for professionals to see the individual in the context of their family/society to provide targeted psychological and social support in the process of redefining self-identity. This we view as processes of strengthening autonomy as well as facilitating participatory enablement, which may lessen the discrepancy between the levels of autonomy expected by the health care system and those experienced by the patient.

The patients in this study that were discharged from the stroke unit to their homes expressed a lack of support. None of the patients interviewed had received ESD services, and it is timely to ask whether ESD in practice equals early discharge. Several participants in this study were discharged to smaller, rural municipalities with widespread population and where comprehensive ESD services are not attainable due to the lack of multidisciplinary competency (Northern Norway Regional Health Authority, 2021). With this in mind, it seems that a unified set of criteria for the evaluation of rehabilitation needs, such as the flowchart of combined mRS and BI- scores used in the Norwegian patient pathway does not serve its purpose of creating equality unless the availability of services at the discharge destination is part of the algorithm.

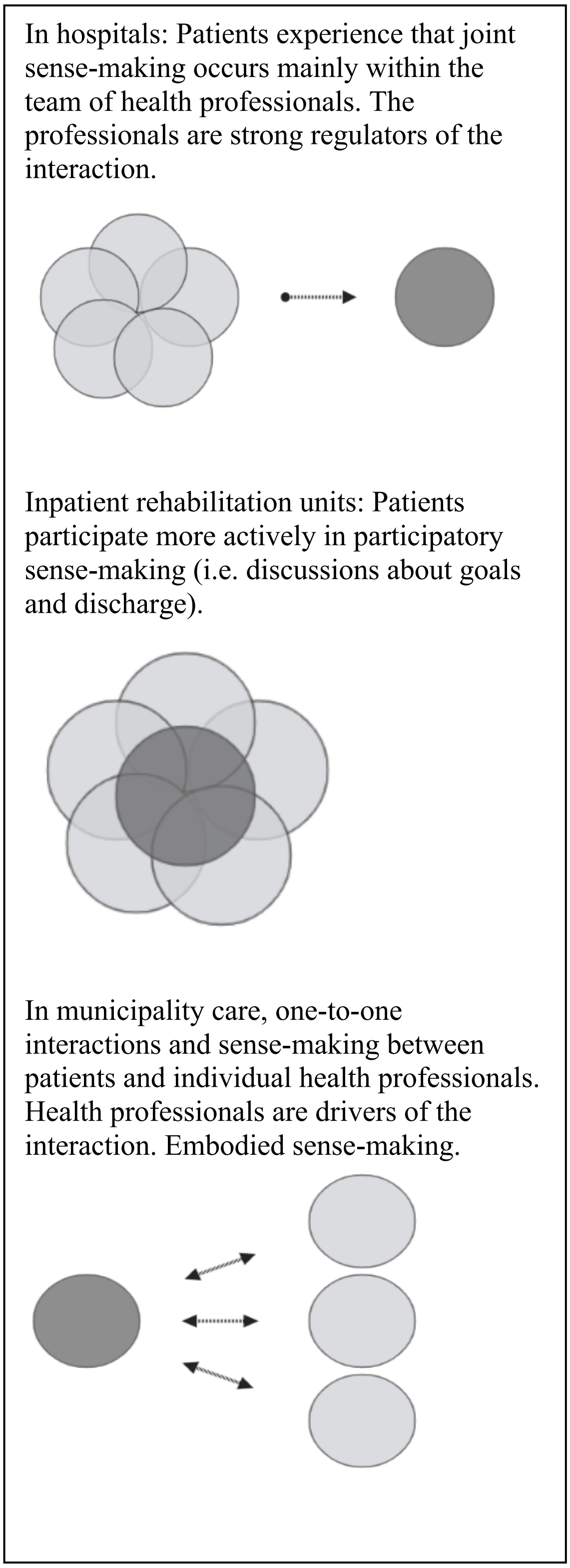
Surprisingly, despite significant recovery of motor function, the transition from being a patient to a person that exercises independently is perceived as difficult and this received little focus at discharge from outpatient physiotherapy at 12 weeks. This seems to be a barrier to making sustainable lifestyle changes of high importance in the secondary prevention of stroke. The measures of physical activity at 12 weeks were low, in line with those found in other studies (Danielsson et al., 2014; Field et al., 2013). Fini et al. (2021) state that, from a health professional perspective, simply advising people who have had strokes to adhere to physical activity guidelines is inadequate. Considering the relatively high levels of functioning at 12 weeks, transitioning from physiotherapy to independent training seems a natural, but difficult, move to make. In both group the SSQOL scale revealed lower scores in the cognitive/mental domains than in those related to physical function. Body functions only capture parts of a person's functioning or disability, and our results highlight that ability does not equal autonomy and participation. The facilitation of community reintegration is an aim of stroke rehabilitation (The Norwegian Directorate of Health, 2017). There seems to be a gap in rehabilitation services regarding the carry-over of improvements in body functions to activity and participation. With this in mind there is a need for closer connections and coordination between health services, in particular physiotherapy and providers of activity and exercise in the community to ease the transition to independent training.

Key benefits and challenges:

- The standardized outcome measures recommended for evaluation early after a stroke provide a narrow view of disability. This was brought forward by discrepancies between experienced and measured levels of disability and is a challenge in assessments of motivation and capacity for further rehabilitation.
- There were no between-group differences on primary outcomes. The usual care group had statistically significant improvements in measures of HRQOL at 12 weeks, but there were no between-group differences on any other secondary outcomes.
- Participants in this study was beneficial for recovery of function, both groups showed significant improvements at the 12-week follow up that aligned with the participants experiences of becoming able.
- Timing and planning of discharge processes varies and may influence patient autonomy and participatory enablement. This can be either a challenge or be beneficial depending on how health professionals involve patients in planning and decision-making.
- There is a gap in rehabilitation services with regards to carry -over of improvements in body functions to activity and participation, including coordination between health services and providers of activity and exercise in the community.

10.1.2 Structures and traditions in institutions and municipalities shape the delivery of care

The integrated findings unveil that the inherent structures and cultures of hospitals, rehabilitation wards and municipality care shape the rehabilitation continuum. These variations in practices surface in terms of the organisation of multidisciplinary teams, communication between patients and health professionals and the delivery of clinical practice. In addition, environmental variations shape the participants perceptions of opportunities for participation and activity. While service delivery is regulated by governance, practices on an institutional level are also shaped by traditions. The different structures of multidisciplinary work shape how involved the patient is in sense-making processes (figure 5). In terms of physiotherapy, the integrated findings revealed variations in the context in which therapy was carried out and in pre-coordinated patterns of behaviour, along with differences in content between groups. These differences were found to be linked both to institutional level of care and to group allocation in the RCT and did not greatly influence satisfaction with treatment.



In hospitals: Patients experience that joint sense-making occurs mainly within the team of health professionals. The professionals are strong regulators of the interaction.

Inpatient rehabilitation units: Patients participate more actively in participatory sense-making (i.e. discussions about goals and discharge).

In municipality care, one-to-one interactions and sense-making between patients and individual health professionals. Health professionals are drivers of the interaction. Embodied sense-making.

Figure 5: Variations in multidisciplinary team structure

10.1.2.1 Variations in organisational structure and environmental affordances impact on participation.

The integrated findings unveil that organisational and environmental structures found in health care shape patients' perceptions of opportunities for participation and activity. Routines and protocols along with pre-coordinated patterns of behaviour, can facilitate or be a barrier to practising a patient-centred approach and supporting the process of becoming able through activity and participation by the patient behalf. The dynamic, affective and social aspects of our interactions with institutions are all various forms of participatory sense-making (De Jaegher, 2013). A spectrum of participation exists in such sense-making within which, in this context, paternalism and autonomy reside at opposite ends and are in part governed by the organisational structure, traditions regarding roles and the physical environment.

Each level of health care shares common features of interaction patterns that transcend different institutions and regions, and can be linked to institutional and professional traditions and the pre-coordination of behaviours (figure 5) (De Jaegher et al., 2016). Such behaviours are precursors to the interaction between a patient and a health professional. Although guided by governance and guidelines, rules are always interpreted in a contextual manner (De Jaegher, 2013). The various team structures entail forms of interaction and sense-making that reside on the spectrum between paternalism and autonomy. The extent to which patients participate should be influenced by to what degree it is in the patients' best interest (Barandiaran, 2017) and can depend, for example, on their health state or the need for rapid medical decisions regarding their care. Awareness of such participation may strengthen ownership of and engagement in the rehabilitation process and should override the traditions and institutional pre-coordinated patterns of behaviour. In this context, the organisation of the multidisciplinary team structure seems to be a potential tool to facilitate partnership in interactions between patients and health professionals and to promote sense-making. Keeping the basic question of enactive theory; what is at stake for this person in this moment? (Di Paolo et al., 2010) in the forefront at all times may aid facilitating a patient-centred approach and limit the autonomy lost "on the assembly line". In doing so, autonomy may be strengthened despite disability.

Our informants report inactivity outside their scheduled activities both in hospitals and in inpatient rehabilitation environments. Enactive theory emphasises the mind-body-environment as a unity (De Jaegher & Di Paolo, 2007). In institutional settings environments seem to be lacking in affordances in terms of activity, apparent in statements like; *"there wasn't much engagement on the ward in terms of activity"* or *"I just lay there waiting".* In this context, affordances are interpreted as what invitations the environment offers an individual (Gibson, 2015). This is in line with literature highlighting a lack of therapeutic activity outside of scheduled sessions and inpatient settings that offer limited opportunities for people to explore their abilities and opportunities (Taylor et al., 2015). The connection between perception and action in phenomenology and enactive theory infers that the environment is always perceived in terms of "what I can do with it" or according to Gibson as affording a range of possible actions (Fuchs & De Jaegher, 2009; Gibson, 2015). The possibility of counteracting inactivity through creating environmental affordances that stimulate engagement and activity is also emerging in research on enriched environments in stroke rehabilitation (McDonald et al., 2018; Qin et al., 2022). It is also supported by theories of motor learning that stress the importance of practising tasks in a meaningful context and a varied manner to aid recovery (Janssen et al., 2022; Levin & Demers, 2020). This line of thought does not, however, explain the measured inactivity at 12 weeks, where the majority of the informants were living in their homes, environments with affordances for activity and learning. Further investigation is therefore required into barriers to physical activity and participation on an individual level.

10.1.2.2 Variations in physiotherapy

The integrated findings reveal variations in physiotherapy practice related to the institutional level of care that surfaces mainly in terms of context and content, the latter of which is shaped by participation in the RCT by the intervention groups. These variations can be seen in connection with the vague recommendations for physiotherapy in the national guidelines (The Norwegian Directorate of Health, 2017) and previous descriptions of rehabilitation services as fragmented and characterised by geographical variations (DiCarlo et al., 2021; EVASAM, 2016; Norrving et al., 2018). One way in which such differences surface in the patients' experiences in this study is through the context in which physiotherapy treatment takes place. Such environments vary from at the patient's hospital ward room to a designated "physiotherapy room", where plinth-based treatments dominate or in a gym environment. The context and approach seem connected and related to the institutional norms and traditions as well as to the therapist's preferences. Mobilisations in the ward environment as recommended in the early post-stroke stage (Langhorne et al., 2017) are frequently not recognised by patients as a physiotherapy measure. These may not comply with expectations regarding physiotherapy as a rehabilitation measure or training. The differences in content between groups were more pronounced in the municipalities than on the rehabilitation wards and this variation was more evident in the usual care group (table 3). The setting did not influence patients' satisfaction with their treatment.

One of the aims of the I-CoreDIST intervention is to facilitate the continuity and equality of care as a patient moves through the different levels of health care after a stroke. I-CoreDIST, was successful in its aim of contributing to less variation in physiotherapy services across the different levels of health care. However, investigations into the reasons behind the higher levels of drop-out in the I-CoreDIST group is needed to further inform whether this coherence is in fact desired by the patients.

Hospital setting (before randomisation)	Physiotherapy mainly in ward environment, mobilisation and stair practice	
In-patient rehabilitation	Usual care group One-to-one plinth/mat-based exercises Gait and stair practice Hands -on facilitation	Intervention group: One-to-one plinth/mat-based exercises Gait and stair practice Exercises based on I-CoreDIST principles Hands-on facilitation
Municipality	Gym environment One-to-one setting and independent training Utilizes equipment such as weights, treadmills and bikes	

Table 3: Treatment context and content

When the informants' experiences are compared to the registration forms filled out by the physiotherapists the differences between the groups are largely confirmed. It seems that the I-CoreDIST interventions was largely delivered according to the programme's intentions and aims. Exercises that demand an active core in combination with 1) sensorimotor activation, 2) selective movement and coordination and 3) the recruitment of large muscle groups in standing positions were favoured. Those combining core activation with concentric and eccentric muscle lengthening and transfers were much less utilized. In the usual care group balance, strength-, gait- and endurance training were the most frequent measures recorded by the physiotherapists. The vast majority had registered that the patients had performed independent exercises in the gym for an average of eight weeks. On this basis, it seems that most of the patients in our study received treatment that was in accordance with the guidelines (The Norwegian Directorate of Health, 2017). The main similarity between the interventions was the training of postural control and balance. The registration forms uncovered some main features of usual care treatment, but a larger sample would be required to make inferences about usual care physiotherapy after strokes in Norway.

Our data suggest that the main overall difference between the groups in terms of content of physiotherapy seems to be a divide between the delivery of treatment focusing on either movement quality or intensity. This divide cannot solely be explained by the opportunities or restrictions resulting from the I-CoreDIST intervention as it encourages both. Rather, I believe this is rooted in a long-standing divide between approaches, which has been apparent in the literature for decades (van Vliet et al., 2005). There is a need to mix established practices in accordance with recommendations from the literature (Pollock et al., 2014) to create physiotherapy practices that align with contemporary motor control theories and knowledge of neuroplastic processes of recovery (Nielsen et al., 2015). In doing so, treatment incorporating quality and a high degree of good variability in movement, which allows the patient to adapt their movements according to different environments, as well as an emphasis on intensity and repetitions, need to be implemented (Levin & Piscitelli, 2022). If the traditional barriers between approaches are overcome there should be no need for high intensity and movement quality to be opposites.

Key benefits and challenges

- Participation in activity and decision-making vary between levels of health care. How multidisciplinary teams are organized seems to be a potential tool to facilitate partnership in interactions and to promote sense-making considered beneficial in strengthening autonomy and participation.
- Inactivity in institutional care is a challenge for recovery and linked to lack of environmental affordances for activity and for exploring abilities and opportunities. Further investigations into barriers to physical activity and participation on an individual level are required.
- Physiotherapy varies in terms of content and context, particularly on a municipality level, yet participants were generally satisfied with treatment. Variations were less pronounced in the I-CoreDIST group indicating its role in providing continuity.
- There is a divide between focus on movement quality or intensity in treatment in contrast to recommendations in the current literature on motor control and neuroplasticity endorsing the benefits of combining approaches.

10.1.3 Embodiment, meaning and progress in physiotherapy interactions

Our findings accentuate that experiencing positive bodily changes, tailored difficulty and intensity are linked to the development of meaning and motivation in physiotherapy. The physiotherapist is expected to take on the role of a mentor, offering motivation, support and guidance and to ensure progress. The physiotherapist's role in post-stroke rehabilitation is emphasised and how they represent continuity is particularly highlighted. These views were shared between the intervention and usual care groups. The participants described satisfaction with their physiotherapy treatments and, positive experiences related to their progress and physical exertion during exercise. These experiences align with the significant overall improvements in postural control (TIS-modNV, SwePass.NV), balance (MiniBESTest) and gait (10MWT preferred pace, 2MWT) observed in both groups between the baseline and 12-week tests and the higher scores in domains of physical function on the SSQOL at 12 weeks. The measured within-group differences seem, to a certain degree to be reflective of the content in training when held together with the participants descriptions. There is a contrast between the unified practices regarding assessments and the variation in the delivery of physiotherapy treatments. Partnership in interaction is a facilitator for participatory sense-making and the creation of meaningful action.

The relatively high dose of physiotherapy during the 12-week period was well tolerated, despite struggles with fatigue. However, improvements at the body structure level seem to have little carry over effect on activity and these findings contrast with the sustained low levels of physical activity measured at 12 weeks. This suggests little uptake of physical activity after the 12-week treatment period. Both groups had their lowest SSQOL-scores in the domain of "energy" and "thinking", indicating that issues with fatigue and cognition could be a challenge in terms of activity and participation

10.1.3.1 Sense-making in physiotherapy — motivation and meaning

The importance of individualised support from one's physiotherapist as a source of motivation during rehabilitation was a common feature, regardless of the approach to physiotherapy adopted and the context. From an enactive point of view experiences are inherently embodied (De Jaegher & Di Paolo, 2007). Interpersonal aspects emerging from the physiotherapy situation such as engagement, motivation and meaning along with progress, shape the patients' experiences. The meaning attributed to the embodied experiences in physiotherapy are important for both compliance and recovery processes (Brodal, 2010; Danzl et al., 2012; Levin & Demers, 2020; Newell & Verhoeven, 2017). This was reinforced as the informants were in the process of making sense of themselves in their post-stroke bodies (Arntzen, Hamran, et al., 2015), and their experiences were important contributors to motivation and hope. In this respect, it is reassuring that the results from the standardized measures of the RCT are in line with experiences of progress. This indicate that the objective measures capture similar bodily changes to those felt and brought forward in the participants accounts.

Experiences of physiotherapy assessments were rather uniform, regardless of group affiliation and the level of health care. These were characterised by testing of i.e. strength, range of motion and transfers and mostly individual sense-making on the physiotherapists' behalf, rather than participatory sense-making between the patient and physiotherapist. Other common features were investigations at the body function level and a third-person perspective of the body. Physiotherapists are encouraged to extend their domain of concern beyond the traditional evaluations of the body function level to include all domains of the ICF to facilitate a holistic approach (Tempest et al., 2013). The I-CoreDIST intervention is founded on a framework that provides subjectivity to the body. The outline of assessment in the I-CoreDIST booklet, emphasises an embodied approach investigating; movement control, the quality of performance, specificity and "explorations of possibilities for change in terms of orienting the patient towards movement possibilities to fuel inner motivation and belief that movement control is possible" (personal communication). It seems that attempts to incorporate such an embodied approach to assessment in the I-CoreDIST intervention diverged from usual practice and were less implemented. This finding aligns with those of others that concluded that changing clinical practice is a slow process (Peters et al., 2023), reliant upon changes in therapists' beliefs (Connell et al., 2018). Interestingly, the lack of participatory sense-making processes in assessment is in contrast to descriptions of the interactions in treatments where both verbal and non-verbal communication and support from the physiotherapist was highlighted as a decisive motivator. Verbal encouragement from the physiotherapists was emphasised as important for motivation during particularly demanding exercises and tasks.

Experiences of sense-making in the therapy situation emerged in different forms, such as the appreciation of physical exertion, the mastery of skills, measurable progressions in strength and endurance or learning experiences during the facilitation of movement in physiotherapy. These variations in sense-making experiences seem connected to the physiotherapy approach. Experience is always shaped by social forces, and intersubjectivity is inherently transgressive, meaning that one's experience is inevitably infiltrated and informed by other people's behaviours and attitudes (Maclaren 2018). The transgression of one person's experience by another is a condition of learning, highlighting physiotherapists' role in teaching and the differences in focus. Meaning was found in terms of progress in the number of repetitions or sets where strength and endurance were emphasised in training. Likewise, movement control was emphasised as meaningful when the quality of movement was central in the physiotherapists approach.

The integrated findings of content and experiences from physiotherapy actualise a link between approaches to physiotherapy treatment, including the context and the physiotherapist's role in participatory sense-making. One way in which this differ is the utilisation of hands on facilitation. Such therapeutic handling was mostly described by participants in the I-CoreDIST group, as was endorsed by the intervention. Movement is significant in sense-making (De Jaegher & Di Paolo, 2007) and joint movements through physical interactions and actions are the language of physiotherapy. In this sense, hands-on therapy as a means of facilitating functional movement is an important tool in participatory sense-making, where the aim is not to help the patient as such, but, rather, when done skilfully to achieve a way of moving together and tacitly making sense of one's body after a stroke. The impact of such facilitation was illustrated by the following statement; "*She held me and forced me forward, I don't mean that she lifted, it was like I had to straighten myself. It felt so right. She was there helping me along with her hands, you could feel it. I can't explain it. It felt like I was able to walk a bit more just after. It did me a lot of good*." These measures can be viewed as affordances of movement in the context of the therapeutic session (Normann, 2020) and serves as an example of how different "languages" are applied in embodied sense-making and learning experiences in physiotherapy practice.

10.1.3.2 Content in treatment and outcomes

In a treatment situation, the physiotherapist is the regulator of the interaction due to their professional knowledge and role (Di Paolo et al., 2018; Thornquist, 2009). This entails a degree of power asymmetry in the interaction and in the sense-making that emerges, evident in the patients' relatively indifferent attitudes towards the content of therapy, and in terms of them trusting the physiotherapists to make the optimal choices. The participants express preferences mainly in terms of wanting to be challenged and pushed. The research-based guidelines (Schaefer et al., 2013), and patient preferences are vague. Hence, in terms of the EBP framework, much emphasis is on institutional traditions and clinical expertise or therapists' preferences to guide the individual physiotherapy course of treatment. The integrated findings indicate that some of the variations in physiotherapy treatment are reflected in the outcomes, supported by the notion that plastic changes and motor learning are experience and learning dependent and often driven by meaningful behaviour (Carey et al., 2019; Levin & Piscitelli, 2022). While the RCT sample was too small to form definite conclusions, some of the differences in the outcomes between the groups are in alignment with experiences of and registrations of physiotherapy input. The intervention group showed significant reductions in sway amplitude in the ML plane with their eyes open and both with eyes open and eyes closed in the AP plane. There is consensus that kinematic measures represent the best tools for distinguishing behavioural restitution (true recovery) and compensation after a stroke, yet no consensus has yet been reached as to which the best parameters are (Kwakkel et al., 2017). We chose to measure sway amplitude as it is a commonly used measure of postural stability (Mansfield & Inness, 2015). Unfortunately, we were unable to perform force plate measurements of symmetry in weight bearing, as this would have added rigour to our interpretations of the results (Kwakkel et al., 2017). The results are cautiously interpreted as improved postural stability and related to the focus on targeting the underlying prerequisites for postural control and balance in the I-CoreDIST intervention.

The usual care group demonstrated significant improvements in terms of the daily average minutes spent in moderate physical activity, the number of steps and the 10MWT fast pace, suggesting that their capability regarding speed and endurance in walking activities was greater than that of the participants in the intervention group. The results are supported by research suggesting that the use of treadmills along with conventional gait training in stroke rehabilitation may improve gait speeds (Mehrholz et al., 2017). The focus on the structured training of strength and endurance shared in the usual care groups and their physiotherapists accounts of the content of physiotherapy treatment aligns well with the results and is supported by research on high-intensity training (Wiener et al., 2019). In addition, these findings support the impression given by the interviews and the registration forms that the I-CoreDIST intervention did not target intensity and endurance sufficiently.

The integrated findings also reveal some paradoxes, highlighting areas in need of further investigation. Experiencing bodily exertion was strongly connected to meaning and provided motivation during plateaus in functional recovery. Such exertion seems to strengthen the embodied self, based on statements like *"it made me feel like my body was working again"* and to provide encouragement for further efforts in training. This finding is surprising when seen in the context of the low levels of physical activity measured after both the baseline and 12-week assessments with zero counts of vigorous physical activity. On this note, it is worth contemplating whether the reliance on the physiotherapist as the regulator and motivator in a treatment situation may be counteractive in terms of a patient becoming independent in terms of physical exercise. Several authors have highlighted the need for health professionals to promote empowerment and self-efficacy to enable patients to continue their processes of recovery outside the rehabilitation context (Arntzen, Hamran, et al., 2015; Gustafsson & Bootle, 2013; Pallesen, 2014). SSQOL-scores were lower in areas of cognitive/mental domains than in those of physical functioning, and as such our results point to the need to investigate their impact upon activity and participation in future studies. Regardless, it seems important that the physiotherapist stimulates engagement and internal motivation. The experienced barriers to independent training and how the meaning found in experiencing exertion in training may be utilised to promote sustained physical activity and training after a stroke are areas that require further investigation

Key benefits and challenges

- Participants found meaning and motivation in experiencing bodily changes, progress and individualised treatment in physiotherapy. Their perceptions of progress align well with measured improvements in postural control, balance and gait in both groups.

- Unified approaches to assessment that were lacking in participatory sense-making processes were in contrast to experiences of active participation during treatment. There was diversity in approaches to physiotherapy treatment, some which are reflected in outcomes.

- Sense-making physiotherapy emerged in different forms such as the appreciation of physical exertion, the mastery of skills, measurable progressions or learning experiences during the facilitation of movement and seem connected to physiotherapy approach.

- Exertion in training was highlighted as and meaningful, yet activity levels were low after the 12-week follow up. There is a need for knowledge of the barriers to exercising independently in the extension of physiotherapy, including the impact of cognitive challenges.

- Investigations into the physiotherapists role in promoting self-efficacy in independent training and physical activity are needed.

In summary, the integrated findings highlight the influence of 1) governance, policy and research, 2) institutional structures and traditions and 3) interpersonal aspects upon delivery of post stroke rehabilitation and physiotherapy as illustrated in Figure 6.

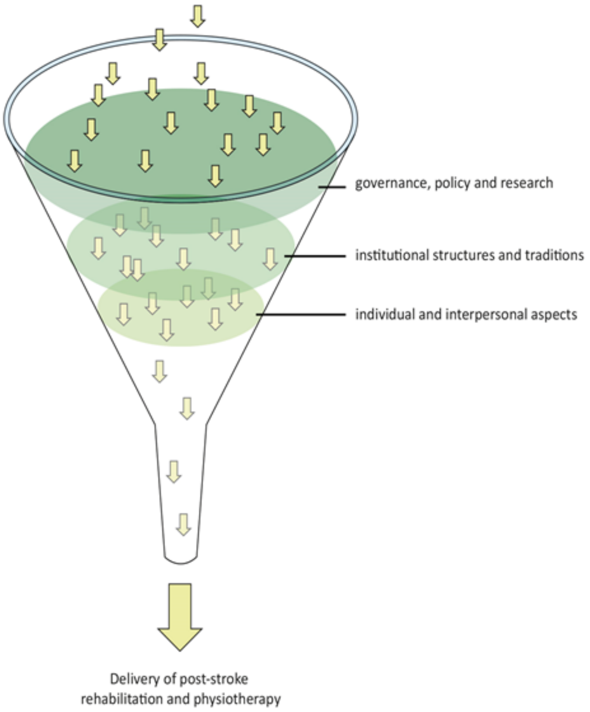


Figure 6: Factors that influence the delivery of post-stroke rehabilitation and physiotherapy on three levels.

10.2 Methodological considerations

In the following the methodological considerations for the mixed method study will be presented and followed byevaluations of the RCT and the interview study. Lastly, I will evaluate the usefulness, relevance and ethics for the study as a whole.

10.2.1 Mixed methods study

Mixed methods research involves combining qualitative and quantitative methods, approaches and concepts that have complementary strengths and nonoverlapping weaknesses (Onwuegbuzie & Johnson, 2006). The methodological considerations of a mixed methods study involve the assessment of the trustworthiness of the different data sets and the subsequent integration of findings. Several frameworks for the evaluation of mixed methods studies have been proposed (Hong et al., 2018; Onwuegbuzie & Johnson, 2006; Tashakkori & Teddlie, 2003); however, a unified practice is lacking (Guetterman et al., 2023). In this study, I have chosen the five questions related to mixed methods found in the Mixed Methods Appraisal Tool version 2018 (Hong et al., 2018), originally developed for the appraisal of quality in systematic mixed studies as the basis for evaluation (table 4). In addition, the methodological considerations for the RCT and the interview study will be evaluated separately in sections 10.2.2 and 10.2.3, respectively.

Is there an adequate rationale for using a mixed methods design to address the research question?	The overall research question involves the investigation of experiences of participation in rehabilitation after a stroke and the effects of I-CoreDIST and usual care physiotherapy. The complexity of the research question calls for exploring these phenomena from both the subjective and objective point of view, with the aim of adding further depth and insight to our findings than either method could alone. In this respect, a mixed methods design is advantageous in terms of extending the understanding of the inherent complex processes of participation, rehabilitation and physiotherapy after a stroke. This mixed method study is anchored within a pragmatic paradigm that enables a mix of methods that contain different views on what constitute knowledge and truths. The resources, time and various experiences required for the data collection, analysis and interpretation are considered a disadvantage in mixed methods research. Regardless, I consider that the nature of the research question and the value added to the results justify the use of this method.

Are the different components of the study effectively integrated to answer the research question?	The study is labelled QUAN+QUAL to indicate that the quantitative and qualitative studies are equal contributors to the mixed methods study. The RCT sample is larger than that of the interview study, and participation in the RCT is a prerequisite for the interviews. However, two of the three papers that form the basis for the mixed methods analysis are based on the qualitative material, and I feel that the equal contribution is just. The parallel mixed design involves data transformation. The quantitative data were transformed into qualitative data through the extraction of the main themes from each paper to enable a thematic analysis of the mixed results. Both data types were re-analysed qualitatively after transformation. Transparency in terms of the method used for the integration of the findings is maintained by the description of the procedure used in the methods section. In addition, these procedures have been documented in the summaries of the findings of each paper, a table outlining the keywords from each summary and the new categories they form. Summaries of the new categories based on these keywords have been provided. This enables the reader to follow the process step by step. During the data transformation process, I continuously moved between the quantitative data, the interpretations of these, the summary of the findings and the keywords extracted to avoid important findings being "lost in translation".
Are the outputs of the integration of the quantitative and qualitative components adequately interpreted?	The thematic process of integration has provided an overview of common themes across the qualitative and quantitative findings to frame the interpretations. The interpretations are informed by relevant literature from both research related to rehabilitation science and health care in today's society. In addition, the use of the ICF and enactive theory serves as a focus for interpretation and support for a more elaborate interpretation of the findings (Malterud, 2015). As a researcher my worldview and preconceptions will always influence my interpretations, an issue that can only be resolved by recognising it. My influence upon these interpretations will be further discussed in section 11.2.3.
Are divergences and inconsistencies between the quantitative and qualitative results adequately addressed?	The interpretation of the integrated findings revealed divergences and inconsistencies. An example is the difference between measured and recollection of experienced disability at baseline. Such findings have been highlighted in the discussion as particularly important issues in need of attention or further investigation. These findings highlight the opportunities within mixed methods to illuminate aspects relating to the research question that neither method could have achieved alone.
Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Established quality criteria have been used for both quantitative and qualitative studies. Regarding the RCT we have adhered to the CONSORT guidelines for reporting parallel group randomised trials. Both qualitative papers are in accordance with the Standards for Reporting Qualitative Research (SRQR).

Table 4: Appraisal of the mixed method study, section five in the Mixed Method Appraisal Tool

10.2.2 RCT

The RCT design has the potential to provide reliable evidence on the effect of interventions. The quality of an RCT depends on the appropriateness of the research question and study design, the prevention and identification of systematic errors (bias), and the use of appropriate analytical techniques (Schulz et al., 2010). We have adhered to the CONSORT recommendations and checklists (Schulz et al., 2010) during the planning, conducting and analysis of results in this RCT. In order to fully judge the validity and reliability of such trials thorough evaluations need to be performed.

10.2.2.1 Preparation, allocation and inclusion (participant selection and sample size)

The research question of this RCT was constructed based on the PICOT format (Population, Intervention, Comparison, Outcome, Time) to enable a clearly defined research focus. Randomisation using a digitalised randomisation tool, and stratifications based on baseline mRS score were performed reduce the risk of bias and to ensure a balanced allocation between the intervention and usual care group (Kang et al., 2008). The assignment sequence was concealed from both the investigators and patients as the randomisation was performed after the completion of the baseline assessment. However, avoiding imbalances by chance and confounders are unavoidable. Identification of the most influential confounders and covariates is not possible when subjects are enrolled one at a time, as is the case in this study (Kang et al., 2008). This means that other issues, such as age and stroke severity, may have influenced the results more than the mRS scores during the baseline assessment.

Based on the eligibility criteria, people with severe strokes are likely to have been excluded based on the need to be able to sit independently for 10 seconds, to be able to follow instructions in physiotherapy and to cooperate during such treatments. This limits our ability to make inferences about the feasibility of I-CoreDIST for patients other than those who have suffered mild and moderate strokes. Still, these criteria were believed be important to improve compliance and retention of participants. The sample size is the estimated number of patients needed to show statistically significant differences. The results from a preceding pilot study (Normann et al., 2019) formed the basis for the required sample size estimation in this study. However, we were not able to recruit the estimated number of participants required (n = 74) in this study (n = 60). This results in the study being underpowered and the analysis being prone to statistical type II errors (not detecting real differences between study groups) (Altman, 1991).

10.2.2.2 Data analysis

ITT analysis is the gold standard when analysing RCT data as it provides results that are the most representative of clinical practice (Gupta, 2011). ITT analysis should be followed per protocol analysis to highlight the impact of non-compliant patients (Gupta, 2011). I did not perform per-protocol analysis, which may be considered a weakness of this RCT. Five participants were excluded and not included in the analysis. This practice is debated within ITT analysis. I chose to discuss each case thoroughly with my supervisors and include clear explanations of the circumstances in the presentation of the findings (Fergusson et al., 2002). We used a wide range of outcome measures to allow for a holistic interpretation of effects from I-CoreDIST and usual care physiotherapy, in terms of including measures covering all the ICF domains and in accordance with recommendations for the evaluation of complex interventions (Skivington et al., 2021). However, Bonferonni corrections, based on the number of outcome measures, were not performed adjust probability. While the usefulness of such corrections is debated, they are believed to reduce the probability of type I errors (concluding that results are statistically significant when they are in fact random). Including Bonferonni correction in this study we would have had to use p to ≤ 0.003 (0.05/13 outcomes) as a criterion for significance, which would not have impacted on the between-group results. It would however have had an impact upon some results for within-group changes in both groups.

10.2.2.3 Internal validity and risk of bias assessment

Our assessment of risk of bias was based on the recommendations made in the Cochrane Collaborations tool for assessing risk of bias (Higgins et al., 2011) and included five possible areas of bias: *selection, performance, detection, attrition and reporting bias. Selection bias* describe bias related to allocation to interventions (Kahan et al., 2015). The baseline data revealed no statistically significant differences between the groups, but we found a trend reflecting higher age, lower premorbid functioning and more severe strokes in the intervention group. This difference was adjusted for by adding the baseline scores to the linear regression model. To target *performance bias*, the study personnel facilitated contact between the physiotherapists in the hospitals and rehabilitation units/municipalities to ensure that the assessors remained blinded to the group allocation. Blinding of personnel is not possible in a clinical physiotherapy trial and introduces a risk of performance bias. To minimise this risk all physiotherapists were instructed not to inform patients regarding their group affiliation to ensure that the participants remained blinded to group allocation. *Detection bias* refers to systematic differences between groups in how outcomes are determined (Higgins et al., 2011). At the baseline testing the participants had not been allocated to a group, hence the outcome assessors were blinded. The assessors were not in contact with the physiotherapists that treated the patients during the study period, and all patients were blinded to group allocation to reduce the risk of detection bias during retest. *Attrition bias* refers to systematic differences between study groups with regard to how many and the ways in which participants are lost from a study. ITT is a means to reduce attrition bias. In our study, five participants were excluded, of whom four were the intervention group. Another seven participants were lost to follow up due to drop-out, six of these were in the intervention group. The comparison between the participants that completed the study and those who were lost during the follow-up phase revealed attrition bias, as the participants that were lost were largely female (6/7), lived alone (6/7) and had a BI after admission that was lower than that of the intervention group (a mean of 75 vs 82.29). *Reporting* *bias* occurs when there are systematic differences between reported and unreported findings. In our study, all the pre-reported outcomes registered at ClinicalTrials.gov were reported, with the exception of pressure map recordings in sitting. These data were not analysed due to a large proportion of missing data due to frequent technical problems during the assessment. In addition, such measurements frequently reached the maximum recordable values and were not considered to be valid.

10.2.3 Interview study

Qualitative methods are inherently different from quantitative methods in terms of their philosophical underpinning and purpose; hence, different frameworks for establishing rigour are needed (Noble & Smith, 2015). In the evaluation of the qualitative parts of this study, I have used the EPICURE tool proposed by Stige et al (2009). The first part of the acronym, EPIC, suggests the challenge of producing rich and substantive accounts based on engagement, processing, interpretation and self-critique. The second part, CURE, refers to the challenge of dealing with preconditions and consequences of research with a focus on critique, usefulness, relevance and ethics. The latter three will be evaluated for study as a whole as they have relevance for the RCT as well as for the interview study.

10.2.3.1 Engagement

Engagement refers to the researcher’s continuous interaction with and relationship to the phenomenon or situation being researched (Stige et al., 2009). As a physiotherapist with a background in stroke rehabilitation, my experiences and interests have influenced the study in several ways. The majority of my clinical experience is in working with people who have had strokes in both the acute and sub-acute stages. This involves providing physiotherapy treatment and coordinating the continuation of treatment following transfers from hospital and rehabilitation wards. This means that I bring my perceptions of positive and negative aspects of the rehabilitation trajectories and preferences regarding the content of physiotherapy. In addition, I have been involved in developing the I-CoreDIST intervention together with two of my supervisors. Disclosing preconceptions is an important tool in transparency in qualitative research (Malterud, 2017). Reflexivity has been maintained through openly discussing and challenging our preconceptions throughout the whole process of planning, collecting data, analysis and writing. My background and engagement in neurological rehabilitation and I-CoreDIST have influenced the development of the interview guide and me as an interviewer. My closeness to the field of investigation may infer both positive and negative impacts upon the results and requires a balancing act between the benefit gained from positioned insight and the exercising of influence upon participants (Brinkmann & Kvale, 2015; Paulgaard, 1997). In conducting interviews, I have made an effort to keep an open mind and make room for doubts, new reflections and surprising findings (Malterud, 2017). In doing so I actively encouraged the informants to share both positive and negative experiences, highlighting the need for both when developing new knowledge.

10.2.3.2 Processing

Systematic and precise processing is an important tool in providing transparency in qualitative research (Malterud, 2012). We have adhered to the recommendations in the SRQR to enhance the quality of this process (O'Brien et al., 2014). The first step towards transparency was the development of a research question and an interview guide to help define the focus of the study. As two of my supervisors and myself were at risk of being too close and personally invested in the subject of inquiry, the diverse backgrounds of the other group members, including a user representative with first-hand experience of living with a stroke, another supervisor who is a neurologist and a co-author who is a philosopher, were important. The diverse backgrounds allowed us to challenge each other with regards to interpretations of findings. The backgrounds of all the co-authors were specified in both qualitative papers.

In addition, the use of STC in the analysis of interview the data and the descriptions of the steps used during this analysis in the method provided transparency as to how the data were interpreted. I used NVivo software in the analysis process, which was of great benefit and allowed for a greater degree of systematisation. In the presentation of the findings, the interview guide and examples of the steps taken in the process of analysis were provided.

To add further rigour to the interpretation of the data member checking, or participant validation could have been carried out. This entails returning the transcribed interviews to the participants to check for accuracy and resonance (Birt et al., 2016). Following considerations of ethical challenges, such as the participants relatively high age, the possibility of cognitive problems such as difficulties with reading and writing and possible distress related to seeing the spoken word in written form out of context (Birt et al., 2016), we decided against conducting member checking.

10.2.3.3 Interpretation

Interpretation involves the act of creating meaning by identifying patterns and developing contexts for the understanding of experiences and descriptions. In the interpretation process, I made a conscious effort to have an open mind and attempt to lay my preconceptions aside in the initial readings of the interview data and the generation of preliminary themes. This implicated being open to the perspectives of other group members and frequently reflecting upon the wider meanings of our findings. In the further analysis of the data, enactive theory functioned as interpretive lenses to enable a wider understanding of how the concepts of embodiment, autonomy and sense-making could inform the informants experiences of participation in the rehabilitation continuum and in physiotherapy. The choice of theory has an impact upon interpretation and was, therefore, explicitly presented in the papers to enable transparency with regard to how the theoretical concepts were used in the analysis.

10.2.3.4 Critique

In this context critique refers to the evaluation of strengths and weaknesses of research (Stige et al., 2009). The limitations and implications of the study were stated in both qualitative papers. Self-critique relates to the researcher-as-instrument in qualitative studies, which is, in part, discussed in the section on *engagement*. Being a physiotherapist who interviews people about their experiences with physiotherapy will influence the process as 1) my interests in and perceptions regarding the field influences how questions are framed and 2) my background will imply a power asymmetry in my interactions with the interviewees. My positioned insight may also be a strength as it could provide a good foundation to understand the informants' experiences and ask relevant follow-up questions, given a conscious awareness of my preconceptions.

10.2.4 Usefulness

For research to be useful it needs to possess value in relation to practical contexts. Evidence based interventions aiming for recovery of function after a stroke and user-based knowledge are called for. I consider both the RCT and interview study to be valuable additions as they evaluate important aspects regarding the usefulness of both a novel intervention and usual care physiotherapy. In addition, important aspects of participation during the rehabilitation continuum are illuminated. These subjects feed directly into the delivery of services to people who have had a stroke and provide valuable insights to aid the evaluation and development of such services.

10.2.5 Relevance

Relevance is concerned with how a study is positioned within and contributes to the knowledgebase of its field. Based on my positioned insights and comprehensive literature reviews in the fields of post-stroke physiotherapy, the rehabilitation continuum and participation after stroke, both the overall and secondary research questions were framed to ensure that these studies addressed areas containing knowledge gaps. Some findings were similar to those of other studies. They might, however, be relevant despite limited novelty. For example, highlighting how issues regarding inactivity after a stroke are sustained despite these having been identified a number of years ago. In addition, the use of the ICF and enactive theory as interpretative lenses highlights different aspects of the findings than other studies within the same field or theme. The knowledge generated from the mixed methods study is relevant to the development of patient centred rehabilitation trajectories and physiotherapy services after a stroke.

10.2.6 Evaluation of complex interventions

Both I-CoreDIST and the comparator, usual care, can be considered complex interventions to which specific evaluation recommendations apply (Skivington et al., 2021). Fidelity is defined as the degree to which implementation of a particular programme follows a programme model and can act as a potential mediator of the relationship between interventions and their intended outcomes (Richards & Hallberg, 2015). The registration forms completed by the physiotherapists delivering the I-CoreDIST intervention had a high return rate (84.2%) and, thus, indicate a degree of fidelity in terms of adherence to the I-CoreDIST intervention. The return rate from the physiotherapists treating patients in the usual care group was lower (48.3%); hence, less confidence exists with regard to whether the reported physiotherapy measures are representative of usual care in the group as a whole. Adding observations of treatments or interviews with the physiotherapists to the mixed methods study would have provided a more thorough investigation into the mapping of usual care physiotherapy. This would also have aided the evaluation of fidelity in the delivery of I-CoreDIST, specifically regarding whether local adaptations were made or in terms of the physiotherapists' beliefs regarding the usefulness of the intervention. This was however, outside the scope of this PhD-project.

10.2.7 Ethics

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Regional Committee of Medical and Health Research Ethics (REK North: 2017/1961) (appendix 3-4) and the data protection officers at both hospitals that recruited participants (appendix 5-6) In addition, the study is registered at ClinicalTrials.gov (Identifier: NCT04069767). All participants provided written informed consent prior to inclusion (appendix 7) and were thoroughly informed about their right to withdraw from the study at any time. The participants were also reassured that withdrawal from this study would not affect their course of rehabilitation. All the interviews and assessments were anonymised. The assessment forms are kept in a locked cabinet and the audio recorded interviews, the transcripts of the interviews and the data sheets are stored on a secure, password-protected server provided by Nordlandssykehuset HF for research purposes.

11 Conclusions and implications

In this thesis, I have presented the condensed findings from three papers (paper I-II) and the synthesis of these through a mixed methods analysis investigating the possible benefits and challenges regarding taking part in a comprehensive individualized physiotherapy intervention (I-CoreDIST) and usual care following an acute stroke along with patient perceptions of participation along the rehabilitation continuum.

The integrated findings highlight how the recommended practices for evaluation early after a stroke provide a narrow view of disability. This was brought forward by discrepancies between experienced and measured levels of disability and is together with little time for rehabilitation in the stroke units a challenge in assessments of motivation and capacity for further rehabilitation. There were no differences between groups following participation in I-CoreDIST or usual care physiotherapy for 12 weeks, except statistically significant improvements in measures of HRQOL in the usual care group. Nevertheless, participation in a 12-week programme of intensive physiotherapy seem beneficial for recovery of function regardless of physiotherapy approach. Both groups showed significant improvements in postural control, balance and gait at the 12-week follow up that aligned with the participants experiences of becoming able.

Practices of active patient involvement in activity and decision-making, for example in discharge processes, varied throughout the rehabilitation continuum and were shaped by governance, levels of health care, institutional traditions and pre-coordinated patterns of behaviours. In this respect, how multidisciplinary teams are organized seems a potential tool to facilitate partnership in interactions and to promote sense-making processes that are considered beneficial in strengthening autonomy and participation. Inactivity in institutional care is a challenge for recovery and linked to lack of environmental affordances for activity and for exploring abilities and opportunities. Further investigations into barriers to physical activity and participation on an individual level are required.

The participants found meaning and motivation in experiencing bodily changes, progress and individualised physiotherapy treatments. Physiotherapy varies in terms of content and context, particularly on a municipality level, yet participants were generally satisfied. There was a contrast between the unified approaches to and the patient's passive role in assessment and experiences of variation and active participation during treatment sessions, the latter a facilitator for participatory sense-making. Variations were less pronounced in the I-CoreDIST group indicating that this intervention was beneficial for providing coherence between levels of health care. There seem to be a divide between focus on movement quality or intensity in treatment, possibly reflected in outcomes. Sense-making emerged in different forms such as the appreciation of physical exertion, the mastery of skills, measurable progressions or learning experiences during the facilitation of movement that seem connected to physiotherapy approach.

Exertion in training was highlighted as and meaningful, yet activity levels were low after the 12-week follow up. There is a gap in rehabilitation services with regards to carry -over of improvements in body functions to activity and participation.

11.1.1 Implications for future research

There is a need for continued effort regarding expanding the knowledgebase of post-stroke rehabilitation and physiotherapy. Such studies should embrace the complexity both post-stroke disability and rehabilitation processes, mixed methods research seems well suited in this respect. Future studies of physiotherapy interventions should incorporate thorough implementation and fidelity evaluations and incorporate studies of effect with sufficient statistical power. Greater efforts should be made into mapping usual care physiotherapy in Norway These should include the physiotherapist point of view to provide valuable information regarding contextual and clinical reasoning factors behind treatment choices. The sustained inactivity of people who have had strokes stroke from the acute stage and into the chronic stage has been highlighted for a long time but seems to remain an unsolved issue of great importance to include in future research.

12 References

Adeoye, O., Nyström, K. V., Yavagal, D. R., Luciano, J., Nogueira, R. G., Zorowitz, R. D., Khalessi, A. A., Bushnell, C., Barsan, W. G., Panagos, P., Alberts, M. J., Tiner, A. C., Schwamm, L. H., & Jauch, E. C. (2019). Recommendations for the Establishment of Stroke Systems of Care: A 2019 Update: A Policy Statement From the American Stroke Association. *Stroke*, *50*(7), e187-e210. https://doi.org/10.1161/STR.0000000000000173

Alexandrov, A. W., Brewer, B. B., Moore, K., Grau, C., Beenstock, D. J., Cudlip, F., Murphy, D. A., Klassman, L., Korsnack, A. M., Johnson, B., Parliament, C. F., Lane, P. C., Walsh, T., Gottbrath, D., Wojner, A. J., DiBiase, S. E., & Alexandrov, A. V. (2019). Measurement of Patients' Perceptions of the Quality of Acute Stroke Services: Development and Validation of the STROKE Perception Report. *Journal of Neuroscience Nursing*, *51*(5), 208-216. https://doi.org/10.1097/jnn.0000000000000471

Altman, D. G. (1991). *Practical statistics for medical research*. Chapman and Hall.

Anderson, S., & Whitfield, K. (2013). Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. *Scandinavian Journal of Caring Sciences*, *27*(4), 820-830. https://doi.org/10.1111/j.1471-6712.2012.01086.x

Arienti, C., Lazzarini, S. G., Pollock, A., & Negrini, S. (2019). Rehabilitation interventions for improving balance following stroke: An overview of systematic reviews. *PLoS One*, *14*(7), e0219781-e0219781. https://doi.org/10.1371/journal.pone.0219781

Aries, A. M., Downing, P., Sim, J., & Hunter, S. M. (2022). Effectiveness of Somatosensory Stimulation for the Lower Limb and Foot to Improve Balance and Gait after Stroke: A Systematic Review. *Brain sciences*, *12*(8). https://doi.org/10.3390/brainsci12081102

Arntzen, C., Borg, T., & Hamran, T. (2015). Long-term recovery trajectory after stroke: an ongoing negotiation between body, participation and self. *Disability and Rehabilitation*, *37*(18), 1626-1634. https://doi.org/10.3109/09638288.2014.972590

Arntzen, C., Hamran, T., & Borg, T. (2015). Body, participation and self transformations during and after in-patient stroke rehabilitation. *Scandinavian journal of disability research : SJDR*, *17*(4), 300-320. https://doi.org/10.1080/15017419.2013.868823

Balakrishnan, R., Kaplan, B., Negron, R., Fei, K., Goldfinger, J. Z., & Horowitz, C. R. (2017). Life after Stroke in an Urban Minority Population: A Photovoice Project. *International Journal of Environmental Research and Public Health*, *14*(3). https://doi.org/10.3390/ijerph14030293

Banks, J. L., & Marotta, C. A. (2007). Outcomes validity and reliability of the modified Rankin scale: Implications for stroke clinical trials - A literature review and synthesis. *Stroke*, *38*(3), 1091-1096. https://doi.org/10.1161/01.STR.0000258355.23810.c6

Barandiaran, X. E. (2017). Autonomy and Enactivism: Towards a Theory of Sensorimotor Autonomous Agency. *Topoi. An International Reiview of Philosophy*, *36*(3), 409-430. https://doi.org/10.1007/s11245-016-9365-4

Benaim, C., Perennou, D. A., Villy, J., Rousseaux, M., & Pelissier, J. Y. (1999). Validation of a standardized assessment of postural control in stroke patients - The Postural Assessment Scale for Stroke patients (PASS). *Stroke*, *30*(9), 1862-1868. https://doi.org/10.1161/01.STR.30.9.1862

Bernhardt, J., Churilov, L., Dewey, H., Donnan, G., Ellery, F., English, C. K., Gao, L., Hayward, K. S., Horgan, F., Indredavik, B., Johns, H., Langhorne, P., Lindley, R., Martins, S., Mohd Ali, K., Middleton, S., Moodie, M., Pandian, J. D., Parsons, B., . . . Thijs, V. (2023). A Phase III, Multi-Arm Multi-Stage Covariate-Adjusted Response-Adaptive Randomised Trial to Determine Optimal Early Mobility Training after Stroke (AVERT DOSE). *International journal of stroke*, 17474930221142207. https://doi.org/10.1177/17474930221142207

Bernhardt, J., Godecke, E., Johnson, L., & Langhorne, P. (2017). Early rehabilitation after stroke. *Current Opinion in Neurology*, *30*(1), 48-54.

Bernhardt, J., Hayward, K. S., Kwakkel, G., Ward, N. S., Wolf, S. L., Borschmann, K., Krakauer, J. W., Boyd, L. A., Carmichael, S. T., Corbett, D., & Cramer, S. C. (2017). Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. *International journal of stroke*, *12*(5), 444-450. https://doi.org/10.1177/1747493017711816

Bernhardt, J., Urimubenshi, G., Gandhi, D. B. C., & Eng, J. J. (2020). Stroke rehabilitation in low-income and middle-income countries: a call to action. *Lancet*, *396*(10260), 1452-1462. https://doi.org/10.1016/S0140-6736(20)31313-1

Billinger, S. A., Arena, R., Bernhardt, J., Eng, J. J., Franklin, B. A., Johnson, C. M., MacKay-Lyons, M., Macko, R. F., Mead, G. E., Roth, E. J., Shaughnessy, M., & Tang, A. (2014). Physical Activity and Exercise Recommendations for Stroke Survivors: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke*, *45*(8), 2532-2553. https://doi.org/10.1161/STR.0000000000000022

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, *26*(13), 1802-1811. https://doi.org/10.1177/1049732316654870

Boehme, C., Toell, T., Lang, W., Knoflach, M., & Kiechl, S. (2021). Longer term patient management following stroke: A systematic review. *International journal of stroke*, *16*(8), 917-926. https://doi.org/10.1177/17474930211016963

Bohannon, R. W. (1997). Comfortable and maximum walking speed of adults aged 20—79 years: reference values and determinants. *Age and Ageing*, *26*(1), 15-19. https://doi.org/10.1093/ageing/26.1.15

Bragstad, L. K., Bronken, B. A., Sveen, U., Hjelle, E. G., Kitzmuller, G., Martinsen, R., Kvigne, K. J., Mangset, M., & Kirkevold, M. (2019). Implementation fidelity in a complex intervention promoting psychosocial well-being following stroke: an explanatory sequential mixed methods study.(Report). *BMC Medical Research Methodology*, *19*(1). https://doi.org/10.1186/s12874-019-0694-z

Breistein, K., Gjelsvik, B. E. B., & Jørgensen, L. (2017). The Postural Assessment Scale for Stroke Patients: translation into Norwegian, cultural adaptation, and examination of reliability. *European Journal of Physiotherapy*, *19*(4), 207-214. https://doi.org/10.1080/21679169.2017.1334817

Bright, F. A. S., Kayes, N. M., Worrall, L., & McPherson, K. M. (2015). A conceptual review of engagement in healthcare and rehabilitation. *Disability and Rehabilitation*, *37*(8), 643-654. https://doi.org/10.3109/09638288.2014.933899

Brinkmann, S., & Kvale, S. (2015). *InterViews: learning the craft of qualitative research interviewing* (3rd ed.). Sage.

Brodal, P. (2010). *The central nervous system. Structure and function.* (Vol. 4th). Oxford University Press.

Bruni, M. F., Melegari, C., De Cola, M. C., Bramanti, A., Bramanti, P., & Calabrò, R. S. (2018). What does best evidence tell us about robotic gait rehabilitation in stroke patients: A systematic review and meta-analysis. *Journal of Clinical Neuroscience*, *48*, 11-17. https://doi.org/10.1016/j.jocn.2017.10.048

Burke, Q., Dodakian, L., See, J., McKenzie, A., Le, V., Wojnowicz, M., Shahbaba, B., & Cramer, S. C. (2015). Neural function, injury, and stroke subtype predict treatment gains after stroke. *Annals of Neurology*, *77*(1), 132-145. https://doi.org/10.1002/ana.24309

Busk, H., Holm, P., Skou, S., Seitner, S., Siemsen, T., & Wienecke, T. (2022). Inter-rater reliability and agreement of 6 Minute Walk Test and 10 Meter Walk Test at comfortable walk speed in patients with acute stroke. *Physiotherapy Theory and Practice*, 1-9. https://doi.org/10.1080/09593985.2022.2030830

Cabrera‐Martos, I., Ortiz‐Rubio, A., Torres‐Sánchez, I., López‐López, L., Jarrar, M., & Valenza, M. C. (2020). The Effectiveness of Core Exercising for Postural Control in Patients with Stroke: A Systematic Review and Meta‐Analysis. *PM&R*, *12*(11), 1157-1168. https://doi.org/10.1002/pmrj.12330

Calabrò, R. S., Sorrentino, G., Cassio, A., Mazzoli, D., Andrenelli, E., Bizzarini, E., Campanini, I., Carmignano, S. M., Cerulli, S., Chisari, C., Colombo, V., Dalise, S., Fundarò, C., Gazzotti, V., Mazzoleni, D., Mazzucchelli, M., Melegari, C., Merlo, A., Stampacchia, G., . . . Bonaiuti, D. (2021). Robotic-assisted gait rehabilitation following stroke: a systematic review of current guidelines and practical clinical recommendations. *European Journal of Physical and Rehabilitation Medicine*, *57*(3), 460-471. https://doi.org/10.23736/s1973-9087.21.06887-8

Cameron, L. J., Wales, K., Casey, A., Pike, S., Jolliffe, L., Schneider, E. J., Christie, L. J., Ratcliffe, J., & Lannin, N. A. (2022). Self-reported quality of life following stroke: a systematic review of instruments with a focus on their psychometric properties. *Quality of Life Research*, *31*(2), 329-342. https://doi.org/10.1007/s11136-021-02944-9

Campos, C., DePaul, V. G., Knorr, S., Wong, J. S., Mansfield, A., & Patterson, K. K. (2018). Validity of the ActiGraph activity monitor for individuals who walk slowly post-stroke. *Topics in Stroke Rehabilitation*, *25*(4), 295-304. https://doi.org/10.1080/10749357.2018.1446487

Carey, L., Walsh, A., Adikari, A., Goodin, P., Alahakoon, D., De Silva, D., Ong, K.-L., Nilsson, M., & Boyd, L. (2019). Finding the Intersection of Neuroplasticity, Stroke Recovery, and Learning: Scope and Contributions to Stroke Rehabilitation. *Neural Plasticity*, *2019*, 5232374-5232315. https://doi.org/10.1155/2019/5232374

Chen, B., Lee, Y. J., & Aruin, A. S. (2015). Anticipatory and compensatory postural adjustments in conditions of body asymmetry induced by holding an object. *Exp Brain Res*, *233*(11), 3087-3096. https://doi.org/10.1007/s00221-015-4377-7

Cheng, D. K.-Y., Dagenais, M., Alsbury-Nealy, K., Legasto, J. M., Scodras, S., Aravind, G., Takhar, P., & Salbach, N. M. (2021). Distance-limited walk tests post-stroke: A systematic review of measurement properties. *NeuroRehabilitation*, *48*(4), 413-439. https://doi.org/10.3233/NRE-210026

Chow, A.-M. D., Shin, J., Wang, H., Kellawan, J. M., & Pereira, H. M. (2022). Influence of Transcranial Direct Current Stimulation Dosage and Associated Therapy on Motor Recovery Post-stroke: A Systematic Review and Meta-Analysis. *Frontiers in aging neuroscience*, *14*, 821915-821915. https://doi.org/10.3389/fnagi.2022.821915

Conforto, A. B., Liew, S.-L., Luft, A. R., Kitago, T., Bernhardt, J., & Arenillas, J. F. (2022). Editorial: Understanding stroke recovery to improve outcomes: From acute care to chronic rehabilitation. *Frontiers in Neurology*, *13*, 1021033-1021033. https://doi.org/10.3389/fneur.2022.1021033

Connell, L. A., Klassen, T. K., Janssen, J., Thetford, C., & Eng, J. J. (2018). Delivering Intensive Rehabilitation in Stroke: Factors Influencing Implementation. *Physical Therapy*, *98*(4), 243-250. https://doi.org/10.1093/ptj/pzy018

Cramer, S. C., & Nudo, R. J. (2010). *Brain repair after stroke*. Cambridge University Press.

Cresswell, J. W., & Poth, C. N. (2018). *Qualitative Inquiry & Research Design. Choosing Among Five Approaches.* (4th ed.). Sage Publications Ltd.

Creswell, J. W., & Creswell, J. D. (2018). *Research design : qualitative, quantitative & mixed methods approaches* (5th edition. ed.). Sage.

Curuk, E., Lee, Y., & Aruin, A. S. (2019). Individuals With Stroke Use Asymmetrical Anticipatory Postural Adjustments When Counteracting External Perturbations. *Motor Control*, *23*(4), 461-471. https://doi.org/10.1123/mc.2018-0083

Danielsson, A. P., Meirelles, C. P. T. P., Willen, C. P., & Sunnerhagen, K. S. M. D. P. (2014). Physical Activity in Community-Dwelling Stroke Survivors and a Healthy Population Is Not Explained by Motor Function Only. *PM&R*, *6*(2), 139-145. https://doi.org/10.1016/j.pmrj.2013.08.593

Danzl, M. M., Etter, N. M., Andreatta, R. D., & Kitzman, P. H. (2012). Facilitating Neurorehabilitation Through Principles of Engagement. *Journal of Allied Health*, *41*(1), 35.

De Jaegher, H. (2013). Rigid and fluid interactions with institutions. *Cognitive systems research*, *25-26*, 19-25. https://doi.org/10.1016/j.cogsys.2013.03.002

De Jaegher, H., & Di Paolo, E. (2007). Participatory sense-making: an enactive approach to social cognition. *Phenomenology and the Cognitive Sciences*, *6*(4), 485-507. https://doi.org/10.1007/s11097-007-9076-9

De Jaegher, H., Peräkylä, A., & Stevanovic, M. (2016). The co-creation of meaningful action: bridging enaction and interactional sociology. *Philosophical Transactions of the Royal Society London. Series B, Biological Sciences*, *371*, https://doi.org/10.1098/rstb.2015.0378. https://doi.org/10.1098/rstb.2015.0378

De Wit, L., Putman, K., Lincoln, N., Baert, Berman, P., Beyens, H., Bogaerts, K., Brinkmann, N., Connell, L., Dejaeger, E., De Weerdt, W., Jenni, W., Lesaffre, E., Leys, M., Louckx, F., Schuback, B., Schupp, W., Smith, B., & Feys, H. (2006). Stroke rehabilitation in Europe - What do physiotherapists and occupational therapists actually do? *Stroke*, *37*(6), 1483-1489. https://doi.org/10.1161/01.STR.0000221709.23293.c2

Della Vecchia, C., Viprey, M., Haesebaert, J., Termoz, A., Giroudon, C., Dima, A., Rode, G., Préau, M., & Schott, A. M. (2021). Contextual determinants of participation after stroke: a systematic review of quantitative and qualitative studies. *Disability and Rehabilitation*, *43*(13), 1786-1798. https://doi.org/10.1080/09638288.2019.1679897

Devlin, N., Roudijk, B., & Ludwig, K. (2022). *Value Sets for EQ-5D-5L : A Compendium, Comparative Review and User Guide*. Springer Nature.

Di Paolo, E., Rohde, M., & De Jaegher, H. (2010). Horizons for the Enactive Mind: Values, Social Interaction and Play. In J. Stewart, O. Gapenne, & E. Di Paolo (Eds.), *Enaction: Toward a New Paradigm for Cognitive Science*. Cambridge: MIT Press.

Di Paolo, E. A., Cuffari, E. C., & De Jaegher, H. (2018). *Linguistic Bodies: The Continuity between Life and Language*. Cambridge: The MIT Press. https://doi.org/10.7551/mitpress/11244.001.0001

DiCarlo, J. A., Gheihman, G., & Lin, D. J. (2021). Reimagining Stroke Rehabilitation and Recovery Across the Care Continuum: Results From a Design-Thinking Workshop to Identify Challenges and Propose Solutions. *Archives of Physical Medicine and Rehabilitation*, *102*(8), 1645-1657. https://doi.org/10.1016/j.apmr.2021.01.074

Dimyan, M. A., & Cohen, L. G. (2011). Neuroplasticity in the context of motor rehabilitation after stroke. *Nat Rev Neurol*, *7*(2), 76-85. https://doi.org/10.1038/nrneurol.2010.200

Dobkin, B. H. (2005). Rehabilitation after Stroke. *The New England journal of medicine*, *352*(16), 1677-1684. https://doi.org/10.1056/NEJMcp043511

Dobkin, B. H., & Carmichael, S. T. (2016). The Specific Requirements of Neural Repair Trials for Stroke. *Neurorehabilitation and Neural Repair*, *30*(5), 470-478. https://doi.org/10.1177/1545968315604400

Dong, Y., Weng, L., Hu, Y., Mao, Y., Zhang, Y., Lu, Z., Shi, T., Du, R., Wang, W., Wang, J., & Wang, X. (2022). Exercise for Stroke Rehabilitation: A Bibliometric Analysis of Global Research From 2001 to 2021. *Frontiers in aging neuroscience*, *14*, 876954-876954. https://doi.org/10.3389/fnagi.2022.876954

Duijnhoven, H. J. R. v., Heeren, A., Peters, M. A., Veerbeek, J. M., Kwakkel, G., Geurts, A. C. H., & Weerdesteyn, V. G. M. (2016). Effects of Exercise Therapy on Balance Capacity in Chronic Stroke: Systematic Review and Meta-Analysis. *Stroke*, *47*(10), 2603-2610. https://doi.org/10.1161/STROKEAHA.116.013839

EuroQol Research Foundation. (2018). *EQ-5D-3L User Guide*. https://euroqol.org/publications/user-guides/

EVASAM. (2016). *Evaluering av samhandlingsreformen*. https://www.forskningsradet.no/siteassets/publikasjoner/1254019340907.pdf

Ezekiel, L., Collett, J., Mayo, N. E., Pang, L., Field, L., & Dawes, H. (2019). Factors Associated With Participation in Life Situations for Adults With Stroke: A Systematic Review. *Archives of Physical Medicine and Rehabilitation*, *100*(5), 945-955. https://doi.org/10.1016/j.apmr.2018.06.017

Fergusson, D., Aaron, S. D., Guyatt, G., & Hébert, P. (2002). Post-randomisation exclusions: the intention to treat principle and excluding patients from analysis. *BMJ*, *325*(7365), 652-654. https://doi.org/10.1136/bmj.325.7365.652

Fernandez-Ballesteros, R., Sanchez-Izquierdo, M., Olmos, R., Huici, C., Ribera Casado, J. M., & Cruz Jentoft, A. (2019). Paternalism vs. Autonomy: Are They Alternative Types of Formal Care? *Front Psychol*, *10*, 1460-1460. https://doi.org/10.3389/fpsyg.2019.01460

Ferreira, A. J., Aguiar, L. T., Martins, J. C., & Faria, C. D. C. d. M. (2022). Stroke survivors with the same levels of exercise as healthy individuals have lower levels of physical activity. *Neurol Sci*, *43*(6), 3729-3735. https://doi.org/10.1007/s10072-021-05578-4

Field, M. J., Gebruers, N., Shanmuga Sundaram, T., Nicholson, S., & Mead, G. (2013). Physical Activity after Stroke: A Systematic Review and Meta-Analysis. *ISRN stroke*, https://doi.org/10.1155/2013/464176. https://doi.org/10.1155/2013/464176

Fini, N. A., Bernhardt, J., Said, C. M., & Billinger, S. A. (2021). How to Address Physical Activity Participation After Stroke in Research and Clinical Practice. *Stroke*, *52*(6), e274-e277. https://doi.org/10.1161/STROKEAHA.121.034557

Fuchs, T., & De Jaegher, H. (2009). Enactive intersubjectivity: participatory sense-making and mutual incorporation. *Phenomenology and the Cognitive Sciences*, *8*, 465-486. https://doi.org/10.1007/s11097-009-9136-4

Gamble, K., Chiu, A., & Peiris, C. (2021). Core Stability Exercises in Addition to Usual Care Physiotherapy Improve Stability and Balance After Stroke: A Systematic Review and Meta-analysis. *Archives of Physical Medicine and Rehabilitation*, *102*(4), 762-775. https://doi.org/10.1016/j.apmr.2020.09.388

GBD 2019 Stroke Collaborators. (2021). Global, regional, and national burden of stroke and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurology*, *20*(10), 795-820. https://doi.org/10.1016/s1474-4422(21)00252-0

Gibson, J. J. (2015). *The ecological approach to visual perception* (Classic edition. ed.). Routledge.

Gjelsvik, B., Breivik, K., Verheyden, G., Smedal, T., Hofstad, H., & Strand, L. I. (2012). The Trunk Impairment Scale - modified to ordinal scales in the Norwegian version. *Disability and Rehabilitation*, *34*(16), 1385-1395. https://doi.org/10.3109/09638288.2011.645113

Gray, J., Lie, M. L. S., Murtagh, M. J., Ford, G. A., McMeekin, P., & Thomson, R. G. (2014). Health state descriptions to elicit stroke values: do they reflect patient experience of stroke? *BMC Health Services Research*, *14*(1), 573-573. https://doi.org/10.1186/s12913-014-0573-6

Gray, V. L., Ivanova, T. D., & Garland, S. J. (2014). Reliability of center of pressure measures within and between sessions in individuals post-stroke and healthy controls. *Gait & Posture*, *40*(1), 198-203. https://doi.org/10.1016/j.gaitpost.2014.03.191

Grefkes, C., & Fink, G. R. (2020). Recovery from stroke: current concepts and future perspectives. *Neurological Research and Practice*, *2*(1), 17-17. https://doi.org/10.1186/s42466-020-00060-6

Guetterman, T. C., Molina-Azorin, J. F., & Fàbregues, S. (2023). The Need to Rigorously Develop Common Quality Guidelines for Reporting Mixed Methods Research. *Journal of mixed methods research*, *17*(1), 6-11. https://doi.org/10.1177/15586898221143561

Gupta, S. K. (2011). Intention-to-treat concept: A review. *Perspectives in Clinical Research*, *2*(3), 109-112. https://doi.org/10.4103/2229-3485.83221

Gustafsson, L., & Bootle, K. (2013). Client and carer experience of transition home from inpatient stroke rehabilitation. *Disability and Rehabilitation*, *35*(16), 1380-1386. https://doi.org/10.3109/09638288.2012.740134

Hamre, C., Botolfsen, P., Tangen, G. G., & Helbostad, J. L. (2017). Interrater and test-retest reliability and validity of the Norwegian version of the BESTest and mini-BESTest in people with increased risk of falling. *BMC Geriatrics*, *17*(1), 92-92. https://doi.org/10.1186/s12877-017-0480-x

Haukelien, H., Vike, H., & Vardheim, I. (2015). *Samhandlingssreformens konsekvenser i de kommunale helse- og omsorgstjenestene. Sykepleieres erfaringer [The consequences of the*

Coordination reform upon municipality health services. Experiences from nurses] (Telemarksforskning-rapport nr. 362, Issue. https://www.telemarksforsking.no/publikasjoner/samhandlingsreformens-konsekvenser-i-de-kommunale-helse-og-omsorgstjenestene/2794/

Hays, R. D., & Reeve, B. B. (2008). Measurement and Modeling of Health-Related Quality of Life. In H. K. Heggenhougen (Ed.), *International Encyclopedia of Public Health* (Vol. 4, pp. 241-252). Elsevier Inc. https://doi.org/10.1016/B978-012373960-5.00336-1

Hellström, K., Lindmark, B., Wahlberg, B., & Fugl-Meyer, A. R. (2003). Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: a prospective investigation. *Journal of rehabilitation medicine*, *35*(5), 202-207. https://doi.org/10.1080/16501970310000836

Higgins, J. P. T., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., Savović, J., Schulz, K. F., Weeks, L., & Sterne, J. A. C. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*, *343*, d5928. https://doi.org/10.1136/bmj.d5928

Hole, E., Stubbs, B., Roskell, C., & Soundy, A. (2014). The patient's experience of the psychosocial process that influences identity following stroke rehabilitation: a metaethnography. *ScientificWorldJournal*, *2014*, 349151. https://doi.org/10.1155/2014/349151

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M.-C., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for information*, *34*(4), 285-291. https://doi.org/10.3233/EFI-180221

Horak, F. B. (2006). Postural orientation and equilibrium: what do we need to know about neural control of balance to prevent falls? *Age and Ageing*, *35*(suppl-2), ii7-ii11. https://doi.org/10.1093/ageing/afl077

Hordacre, B., Austin, D., Brown, K. E., Graetz, L., Pareés, I., De Trane, S., Vallence, A.-M., Koblar, S., Kleinig, T., McDonnell, M. N., Greenwood, R., Ridding, M. C., & Rothwell, J. C. (2021). Evidence for a Window of Enhanced Plasticity in the Human Motor Cortex Following Ischemic Stroke. *Neurorehabilitation and Neural Repair*, *35*(4), 307-320. https://doi.org/10.1177/1545968321992330

Hugues, A., Marco, J. D., Ribault, S., Ardaillon, H., Janiaud, P., Xue, Y., Zhu, J., Pires, J., Khademi, H., Rubio, L., Bernal, P. H., Bahar, Y., Charvat, H., Szulc, P., Ciumas, C., Won, H., Cucherat, M., Bonan, I., Gueyffier, F., & Rode, G. (2019). Limited evidence of physical therapy on balance after stroke: A systematic review and meta-analysis [Review]. *PLoS One*, *14*(8), Article e0221700. https://doi.org/10.1371/journal.pone.0221700

Hunger, M., Sabariego, C., Stollenwerk, B., Cieza, A., & Leidl, R. (2012). Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing rehabilitation. *Quality of Life Research*, *21*(7), 1205-1216. https://doi.org/10.1007/s11136-011-0024-3

Isho, T., & Usuda, S. (2015). Association of trunk control with mobility performance and accelerometry-based gait characteristics in hemiparetic patients with subacute stroke. *Gait & Posture*, *44*, 89-93. https://doi.org/10.1016/j.gaitpost.2015.11.011

Janssen, H., Bird, M.-L., Luker, J., McCluskey, A., Blennerhassett, J., Ada, L., Bernhardt, J., & Spratt, N. J. (2022). Stroke survivors' perceptions of the factors that influence engagement in activity outside dedicated therapy sessions in a rehabilitation unit: A qualitative study. *Clinical Rehabilitation*, *36*(6), 822-830. https://doi.org/10.1177/02692155221087424

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a Definition of Mixed Methods Research. *Journal of mixed methods research*, *1*(2), 112-133. https://doi.org/10.1177/1558689806298224

Kahan, B. C., Rehal, S., & Cro, S. (2015). Risk of selection bias in randomised trials. *Trials*, *16*, 405. https://doi.org/10.1186/s13063-015-0920-x

Kang, M., Ragan, B. G., & Park, J. H. (2008). Issues in outcomes research: an overview of randomization techniques for clinical trials. *Journal of Athletic Training*, *43*(2), 215-221. https://doi.org/10.4085/1062-6050-43.2.215

Karthikbabu, S., & Verheyden, G. (2021). Relationship between trunk control, core muscle strength and balance confidence in community-dwelling patients with chronic stroke. *Topics in Stroke Rehabilitation*, *28*(2), 88-95. https://doi.org/10.1080/10749357.2020.1783896

Kauhanen, M.-L., Korpelainen, J. T., Hiltunen, P., Nieminen, P., Sotaniemi, K. A., & Myllylä, V. V. (2000). Domains and determinants of quality of life after stroke caused by brain infarction. *Archives of Physical Medicine and Rehabilitation*, *81*(12), 1541-1546. https://doi.org/10.1053/apmr.2000.9391

Kaushik, V., & Walsh, C. A. (2019). Pragmatism as a Research Paradigm and Its Implications for Social Work Research. *Social Sciences*, *8*, 255.

Kibler, W. B., Press, J., & Sciascia, A. (2006). The Role of Core Stability in Athletic Function. *Sports Medicine*, *36*(3), 189-198. https://doi.org/10.2165/00007256-200636030-00001

Kogan, E., Twyman, K., Heap, J., Milentijevic, D., Lin, J. H., & Alberts, M. (2020). Assessing stroke severity using electronic health record data: a machine learning approach. *BMC Medical Informatics and Decision Making*, *20*(1), 8. https://doi.org/10.1186/s12911-019-1010-x

Kosak, M., & Smith, T. (2005). Comparison of the 2-, 6-, and 12-minute walk tests in patients with stroke. *Journal of Rehabilitation Research & Development*, *42*(1), 103-107. https://www.ncbi.nlm.nih.gov/pubmed/15742254

Kwakkel, G., Lannin, N. A., Borschmann, K., English, C., Ali, M., Churilov, L., Saposnik, G., Winstein, C., Van Wegen, E. E. H., Wolf, S. L., Krakauer, J. W., & Bernhardt, J. (2017). Standardized Measurement of Sensorimotor Recovery in Stroke Trials: Consensus-Based Core Recommendations from the Stroke Recovery and Rehabilitation Roundtable. *Neurorehabilitation and Neural Repair*, *31*(9), 784-792. https://doi.org/10.1177/1545968317732662

Langhorne, P. (2021). The Stroke Unit Story: Where Have We Been and Where Are We Going? *Cerebrovascular Diseases*, *50*(6), 636-643. https://doi.org/10.1159/000518934

Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke Care 2: Stroke rehabilitation. *The Lancet (British edition)*, *377*(9778), 1693-1702. https://doi.org/10.1016/S0140-6736(11)60325-5

Langhorne, P., Coupar, F., & Pollock, A. (2009). Motor recovery after stroke: a systematic review. *Lancet Neurology*, *8*(8), 741-754. https://doi.org/10.1016/S1474-4422(09)70150-4

Langhorne, P., & Ramachandra, S. (2020). Organised inpatient (stroke unit) care for stroke: network meta‐analysis. *Cochrane Database of Systematic Reviews*(4). https://doi.org/10.1002/14651858.CD000197.pub4

Langhorne, P., Wu, O., Rodgers, H., Ashburn, A., & Bernhardt, J. (2017). A Very Early Rehabilitation Trial after stroke (AVERT): a phase III, multicentre, randomised controlled trial. *Health Technology Assessment*, *21*(54), 1-120. https://doi.org/10.3310/hta21540

Latash, M. L. (2012a). The bliss (not the problem) of motor abundance (not redundancy). *Experimental Brain Research*, *217*(1), 1-5. https://doi.org/10.1007/s00221-012-3000-4

Latash, M. L. (2012b). *Fundamentals of Motor Control*. San Diego: Elsevier Science & Technology. https://doi.org/10.1016/C2011-0-05693-4

Lee, Y., An, S., & Lee, G. (2018). Clinical utility of the modified trunk impairment scale for stroke survivors. *Disability and Rehabilitation*, *40*(10), 1200-1205. https://doi.org/10.1080/09638288.2017.1282990

Levin, M. F., & Demers, M. (2020). Motor learning in neurological rehabilitation. *Disability and Rehabiltation*, 1-9. https://doi.org/10.1080/09638288.2020.1752317

Levin, M. F., Kleim, J. A., & Wolf, S. L. (2009). What Do Motor "Recovery" and "Compensation" Mean in Patients Following Stroke? *Neurorehabilitation and Neural Repair*, *23*(4), 313-319. https://doi.org/10.1177/1545968308328727

Levin, M. F., & Piscitelli, D. (2022). Motor Control: A Conceptual Framework for Rehabilitation. *Motor Control*, *26*(4), 497-517. https://doi.org/10.1123/mc.2022-0026

Lexell, J., & Brogardh, C. (2015). The use of ICF in the neurorehabilitation process. *NeuroRehabilitation*, *36*(1), 5-9. https://doi.org/10.3233/NRE-141184

Li, S., Francisco, G. E., & Zhou, P. (2018). Post-stroke Hemiplegic Gait: New Perspective and Insights. *Frontiers in Physiology*, *9*, 1021-1021. https://doi.org/10.3389/fphys.2018.01021

Liu, S., Levine, S. R., & Winn, H. R. (2010). Targeting ischemic penumbra: part I - from pathophysiology to therapeutic strategy. *Journal of experimental stroke & translational medicine*, *3*(1), 47-55. https://doi.org/10.6030/1939-067x-3.1.47

Luker, J., Lynch, E., Bernhardsson, S., Bennett, L., & Bernhardt, J. (2015). Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies [Review]. *Archives of Physical Medicine and Rehabilitation*, *96*(9), 1698-1708. https://doi.org/10.1016/j.apmr.2015.03.017

Luo, L., Meng, H., Wang, Z., Zhu, S., Yuan, S., Wang, Y., & Wang, Q. (2020). Effect of high-intensity exercise on cardiorespiratory fitness in stroke survivors: A systematic review and meta-analysis. *Annals of Physical and Rehabilitation Medicine 63*(1), 59-68. https://doi.org/10.1016/j.rehab.2019.07.006

MacDonald, G. A., Kayes, N. M., & Bright, F. (2013). Barriers and facilitators to engagement in rehabilitation for people with stroke: a review of the literature. *New Zealand Journal of Physiotherapy*, *41*(3), 112-121. https://doi.org/10.1097/RNJ.0000000000000340

Mallinson, T. P., & Hammel, J. P. (2010). Measurement of Participation: Intersecting Person, Task, and Environment. *Archives of Physical Medicine and Rehabilitation*, *91*(9), 29-33. https://doi.org/10.1016/j.apmr.2010.04.027

Malterud. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, *40*(8), 795-805. https://doi.org/10.1177/1403494812465030

Malterud, K. (2015). Theory and interpretation in qualitative studies from general practice: why and how? *Scandinavian Journal of Public Health 44*(2), 120-129. https://doi.org/10.1177/1403494815621181

Malterud, K. (2017). *Kvalitative metoder i medisinsk og helsefaglig forskning. En innføring* (Vol. 4). Universitetsforlaget.

Mansfield, A., & Inness, E. L. (2015). Force Plate Assessment of Quiet Standing Balance Control: Perspectives on Clinical Application Within Stroke Rehabilitation. *Rehabilitation process and outcome*, *2015*(2015), RPO.S20363. https://doi.org/10.4137/RPO.S20363

Marques-Sule, E., Arnal-Gómez, A., Buitrago-Jiménez, G., Suso-Martí, L., Cuenca-Martínez, F., & Espí-López, G. V. (2021). Effectiveness of Nintendo Wii and Physical Therapy in Functionality, Balance, and Daily Activities in Chronic Stroke Patients. *Journal of the American Medical Directors Association*, *22*(5), 1073-1080. https://doi.org/10.1016/j.jamda.2021.01.076

Mattlage, A. E., Redlin, S. A., Rippee, M. A., Abraham, M. G., Rymer, M. M., & Billinger, S. A. (2015). Use of Accelerometers to Examine Sedentary Time on an Acute Stroke Unit. *Journal of Neurologic Physical Therapy*, *39*(3), 166-171. https://doi.org/10.1097/npt.0000000000000092

McDonald, M. W., Hayward, K. S., Rosbergen, I. C. M., Jeffers, M. S., & Corbett, D. (2018). Is Environmental Enrichment Ready for Clinical Application in Human Post-stroke Rehabilitation? *Frontiers in Behavoural Neuroscience*, *12*, 135-135. https://doi.org/10.3389/fnbeh.2018.00135

Mehrholz, J., Thomas, S., & Elsner, B. (2017). Treadmill training and body weight support for walking after stroke. *The Cochrane Database of Systematic Reviews*, *8*(8), CD002840. https://doi.org/10.1002/14651858.CD002840.pub4

Mehrholz, J., Thomas, S., Werner, C., Kugler, J., Pohl, M., Elsner, B., & Mehrholz, J. (2020). Electromechanical‐assisted training for walking after stroke. *The Cochrane Database of Systematic Reviews*, *2017*(5), CD006185-CD006185. https://doi.org/https://doi.org/10.1002/14651858.CD006185.pub5

Merleau-Ponty, M. (2008). *Phenomenology of perception*. Routhledge Classics.

Nascimento, L. R., Boening, A., Galli, A., Polese, J. C., & Ada, L. (2021). Treadmill walking improves walking speed and distance in ambulatory people after stroke and is not inferior to overground walking: a systematic review. *Journal of Physiotherapy*, *67*(2), 95-104. https://doi.org/10.1016/j.jphys.2021.02.014

Newell, K. M., & Verhoeven, F. M. (2017). Movement rehabilitation: are the principles of re-learning in the recovery of function the same as those of original learning? *Disability and Rehabilitation*, *39*(2), 121-126. https://doi.org/10.3109/09638288.2016.1170895

Ng, S. S. M. (2011). Contribution of subjective balance confidence on functional mobility in subjects with chronic stroke. *Disability and Rehabilitation*, *33*(22-23), 2291-2298. https://doi.org/10.3109/09638288.2011.568667

Nielsen, J. B., Willerslev-Olsen, M., Christiansen, L., Lundbye-Jensen, J., & Lorentzen, J. (2015). Science-based neurorehabilitation: recommendations for neurorehabilitation from basic science. *Journal of motor behavior*, *47*(1), 7-17. https://doi.org/10.1080/00222895.2014.931273

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evid Based Nurs*, *18*(2), 34-35. https://doi.org/10.1136/eb-2015-102054

Nord-Trøndelag Hospital Trust. (2021). *Nøkkeltall Helse Nord-Trøndelag [Key figures for Nord-Trøndelag Hospital Trust]*. Nord-Trøndelag Hospital Trust,. https://hnt.no/om-oss#nokkeltall-helse-nord-trondelag

Nordland Hospital Trust. (2017). *Nordlandssykehuset HF for fremtiden. Strategisk utviklingsplan 2035 [Nordland Hospital Trust for the future. Strategic development plan 2035]*. https://nordlandssykehuset.no/Documents/Nordlandssykehuset%20for%20framtiden/Strategisk%20utviklingsplan%20for%20NLSH,%202017-2035/Ledersamling_NLSH_2017_del1.pdf

Normann, B. (2020). Facilitation of movement: new perspectives provide expanded insights to guide clinical practice. *Physiotherapy Theory and Practice*, *36*(7), 769-778. https://doi.org/10.1080/09593985.2018.1493165

Normann, B., Arntzen, E. C., & Sivertsen, M. (2019). Comprehensive core stability intervention and coordination of care in acute and subacute stroke rehabilitation-a pilot study. *European Journal of Physiotherapy*, *21*(4), 187-196. https://doi.org/10.1080/21679169.2018.1508497

Normann, B., Zanaboni, P., & Arntzen, E. C. (2016). Innovative Physiotherapy and Continuity of Care in People with Multiple Sclerosis: A Randomized Controlled Trial and a Qualitative Study. *Journal of Clinical Trials*, *6*(5). https://doi.org/10.4172/2167-0870.1000282

Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., Kutluk, K., Mikulik, R., Wardlaw, J., Richard, E., Nabavi, D., Molina, C., Bath, P. M., Stibrant Sunnerhagen, K., Rudd, A., Drummond, A., Planas, A., & Caso, V. (2018). Action Plan for Stroke in Europe 2018-2030. *European Stroke Journal*, *3*(4), 309-336. https://doi.org/10.1177/2396987318808719

Northern Norway Regional Health Authority. (2021). *Rehabilitering i Nord-Norge. Rapport fra et prosjektarbeid for et likeverdig og mer forutsigbart rehabiliteringstilbud i Nord-Norge [Rehabilitation in North Norway. Report from a project for equality and more predictable rehabilitation services in North Norway]*. https://helse-nord.no/Documents/Fagplaner%20og%20rapporter/Rapporter%20og%20dokumenter/Rehabilitering%20i%20Nord-Norge%20-%20endelig%20prosjektrapport.pdf

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, *89*(9), 1245-1251. https://doi.org/10.1097/acm.0000000000000388

O'Donnell, M. J. D., Chin, S. L., Rangarajan, S. M., Xavier, D. P., Liu, L. P., Zhang, H. P., Rao-Melacini, P. M., Zhang, X. M., Pais, P. P., Agapay, S. B., Lopez-Jaramillo, P. P., Damasceno, A. M. D., Langhorne, P. P., McQueen, M. J. P., Rosengren, A. P., Dehghan, M. P., Hankey, G. J. P., Dans, A. L. P., Elsayed, A. P., . . . Yusuf, S. P. (2016). Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. *Lancet*, *388*(10046), 761-775. https://doi.org/10.1016/S0140-6736(16)30506-2

Obembe, A. O., & Eng, J. J. (2016). Rehabilitation Interventions for Improving Social Participation After Stroke: A Systematic Review and Meta-analysis. *Neurorehabilitation and Neural Repair*, *30*(4), 384-392. https://doi.org/10.1177/1545968315597072

Onwuegbuzie, A. J., & Johnson, R. B. (2006). The Validity Issue in Mixed Research. *Research in the schools*, *13*(1), 48. https://ocd.lcwu.edu.pk/cfiles/Gender%20&%20Development%20Studies/GDS-502/Thevalidityissueinmixedresearch.pdf#page=55

Onwuegbuzie, A. J., Johnson, R. B., & Collins, K. M. T. (2009). Call for mixed analysis: A philosophical framework for combining qualitative and quantitative approaches. *International Journal of Multiple Research Approaches*, *3*, 114-139. https://doi.org/10.5172/mra.3.2.114

Owolabi, M. O., Thrift, A. G., Martins, S., Johnson, W., Pandian, J., Abd-Allah, F., Varghese, C., Mahal, A., Yaria, J., Phan, H. T., Roth, G., Gall, S. L., Beare, R., Phan, T. G., Mikulik, R., Norrving, B., Feigin, V. L., Abera, S. F., Addissie, A., . . . Yperzeele, L. (2021). The state of stroke services across the globe: Report of World Stroke Organization–World Health Organization surveys. *International journal of stroke*, *16*(8), 889-901. https://doi.org/10.1177/17474930211019568

Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disability and Rehabilitation*, *36*(3), 232-241. https://doi.org/10.3109/09638288.2013.788217

Paulgaard, G. (1997). Feltarbeid i egen kultur: innenfra, utefra eller begge deler? [Fieldwork in their own culture: from within, from outside or both?]. In E. Fossåskåret, O. L. Fuglestad, & T. H. Aase (Eds.), *Metodisk feltarbeid. Produksjon og tolkning av kvalitative data. [Methodical fieldwork. Production and interpretation of qualitative data]* (pp. 70-93). Universitetsforlaget.

Pedersen, S. G., Heiberg, G. A., Nielsen, J. F., Friborg, O., Stabel, H. H., Anke, A., & Arntzen, C. (2018). Validity, reliability and Norwegian adaptation of the Stroke-Specific Quality of Life (SS-QOL) scale. *SAGE Open Medicine*, *6*, 2050312117752031-2050312117752031. https://doi.org/10.1177/2050312117752031

Persson, C. U., Hansson, P.-O., & Sunnerhagen, K. S. (2011). Clinical tests performed in acute stroke identify the risk of falling during the first year: postural stroke study in Gothenburg (POSTGOT). *Journal of rehabilitation medicine*, *43*(4), 348-353. https://doi.org/10.2340/16501977-0677

Peters, S., Lim, S. B., Bayley, M. T., Best, K., Connell, L. A., Corriveau, H., Donkers, S. J., Dukelow, S. P., Klassen, T. D., Milot, M.-H., Sakakibara, B. M., Sheehy, L., Wong, H., Yao, J., & Eng, J. J. (2023). Implementation of increased physical therapy intensity for improving walking after stroke: Walk ’n watch protocol for a multisite stepped-wedge cluster-randomized controlled trial. *International journal of stroke*, *18*(1), 117-122. https://doi.org/10.1177/17474930221129982

Phan, H. T., Blizzard, C. L., Reeves, M. J., Thrift, A. G., Cadilhac, D. A., Sturm, J., Heeley, E., Otahal, P., Rothwell, P., Anderson, C. S., Parmar, P., Krishnamurthi, R., Barker-Collo, S., Feigin, V., & Gall, S. (2019). Sex Differences in Long-Term Quality of Life Among Survivors After Stroke in the INSTRUCT. *Stroke*, *50*(9), 2299-2306. https://doi.org/10.1161/STROKEAHA.118.024437

Pollock, A., Baer, G., Campbell, P., Choo, P. L., Forster, A., Morris, J., Pomeroy, V. M., & Langhorne, P. (2014). Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database of Systematic Reviews*(4). https://doi.org/10.1002/14651858.CD001920.pub3

Qin, H., Reid, I., Gorelik, A., & Ng, L. (2022). Environmental Enrichment Following Stroke. *Stroke*, *53*(6), e230. https://doi.org/10.1161/STROKEAHA.121.038147

Rabin, R., & de Charro, F. (2001). EQ-5D: a measure of health status from the EuroQol Group. *Annals of Medicine*, *33*(5), 337-343.

Raghavan, P. (2015). Upper Limb Motor Impairment After Stroke. *Physical Medicine and Rehabilitation Clinics of North America*, *26*(4), 599-610. https://doi.org/10.1016/j.pmr.2015.06.008

Richards, D. A., & Hallberg, I. R. (2015). *Complex Interventions in Health: An Overview of Research Methods* (Vol. 2). Ringgold Inc.

Roenn-Smidt, H., Jensen, M., & Pallesen, H. (2021). Body and identity in physiotherapy after stroke. *Physiotherapy Theory and Practice*, *37*(10), 1067-1079. https://doi.org/10.1080/09593985.2019.1681041

Rosenblum, M., & van der Laan, M. J. (2009). Using regression models to analyze randomized trials: asymptotically valid hypothesis tests despite incorrectly specified models. *Biometrics*, *65*(3), 937-945. https://doi.org/10.1111/j.1541-0420.2008.01177.x

Sampaio-Baptista, C., Sanders, Z.-B., & Johansen-Berg, H. (2018). Structural Plasticity in Adulthood with Motor Learning and Stroke Rehabilitation. *Annual Review of Neuroscience*, *41*(1), 25-40. https://doi.org/10.1146/annurev-neuro-080317-062015 (Annual Review of Neuroscience)

Saunders, D. H., Mead, G. E., Fitzsimons, C., Kelly, P., van Wijck, F., Verschuren, O., Backx, K., & English, C. (2021). Interventions for reducing sedentary behaviour in people with stroke. *Cochrane Database of Systematic Reviews*(6). https://doi.org/10.1002/14651858.CD012996.pub2

Saunders, D. H., Sanderson, M., Hayes, S., Johnson, L., Kramer, S., Carter, D. D., Jarvis, H., Brazzelli, M., & Mead, G. E. (2020). Physical fitness training for stroke patients. *Cochrane Database of Systematic Reviews*(3). https://doi.org/10.1002/14651858.CD003316.pub7

Schaefer, S. Y., Patterson, C. B., & Lang, C. E. (2013). Transfer of Training Between Distinct Motor Tasks After Stroke: Implications for Task-Specific Approaches to Upper-Extremity Neurorehabilitation. *Neurorehabilitation and Neural Repair*, *27*(7), 602-612. https://doi.org/10.1177/1545968313481279

Schulz, K. F., Altman, D. G., & Moher, D. (2010). CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMC Medicine*, *8*, 18. https://doi.org/10.1186/1741-7015-8-18

Scrivener, K., Dean, C., Cameron, I. D., & Ada, L. (2022). Stroke in Australia: long term survivors have fallen into a black hole. *Medical journal of Australia*, *217*(6), 290-291. https://doi.org/10.5694/mja2.51691

Scurlock-Evans, L., Upton, P., & Upton, D. (2014). Evidence-Based Practice in physiotherapy: a systematic review of barriers, enablers and interventions. *Physiotherapy*, *100*(3), 208-219. https://doi.org/https://doi.org/10.1016/j.physio.2014.03.001

Sehatzadeh, S. (2015). Effect of Increased Intensity of Physiotherapy on Patient Outcomes After Stroke: An Evidence-Based Analysis. *Ontario Health Technology Assessment Series*, *15*(6), 1-42. https://www.ncbi.nlm.nih.gov/pubmed/26356355

Selzer, M. E. (2014). *Textbook of neural repair and rehabilitation. : Volume 1, : Neural repair and plasticity* (Second ed., Vol. 1). Cambridge University Press.

Shah, S., Vanclay, F., & Cooper, B. (1989). Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of Clinical Epidemiology*, *42*(8), 703-709. https://doi.org/10.1016/0895-4356(89)90065-6

Shaw, J. A., Connelly, D. M., & Zecevic, A. A. (2010). Pragmatism in practice: mixed methods research for physiotherapy. *Physiotherapy Theory and Practice*, *26*(8), 510-518. https://doi.org/10.3109/09593981003660222

Shumway-Cook, A., Shumway-Cook, A., Woollacott, M. H., Rachwani, J., & Santamaria, V. (2022). *Motor control : translating research into clinical practice* (Sixth ed.). Lippincott Williams & Wilkins.

Sivertsen, M., & Normann, B. (2015). Embodiment and self in reorientation to everyday life following severe traumatic brain injury. *Physiotherapy Theory and Practice*, *31*(3), 153-159. https://doi.org/10.3109/09593985.2014.986350

Sjoholm, A., Skarin, M., Churilov, L., Nilsson, M., Bernhardt, J., & Linden, T. (2014). Sedentary behaviour and physical activity of people with stroke in rehabilitation hospitals. *Stroke Research and Treatment*, *2014*, 591897. https://doi.org/10.1155/2014/591897

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*, *374*, n2061-n2061. https://doi.org/10.1136/bmj.n2061

Solbakken, L. M., Nordhaug, M., & Halvorsen, K. (2022). Patients' experiences of involvement, motivation and coping with physiotherapists during subacute stroke rehabilitation - a qualitative study. *European Journal of Physiotherapy*, *ahead-of-print*, 1-8. https://doi.org/10.1080/21679169.2022.2032825

Stergiou, N. (2004). *Innovative analyses of human movement.* . Human Kinetics.

Stige, B., Malterud, K., & Midtgarden, T. (2009). Toward an Agenda for Evaluation of Qualitative Research. *Qualitative Health Research*, *19*(10), 1504-1516. https://doi.org/10.1177/1049732309348501

Tashakkori, A., & Teddlie, C. (2003). *Handbook of mixed methods in social & behavioral research*. SAGE.

Taylor, E., McKevitt, C., & Jones, F. (2015). Factors shaping the delivery of acute inpatient stroke therapy: a narrative synthesis. *Journal of rehabilitation medicine*, *47*(2), 107-119. https://doi.org/10.2340/16501977-1918

Teasell, R., Salbach, N. M., Foley, N., Mountain, A., Cameron, J. I., Jong, A. d., Acerra, N. E., Bastasi, D., Carter, S. L., Fung, J., Halabi, M.-L., Iruthayarajah, J., Harris, J., Kim, E., Noland, A., Pooyania, S., Rochette, A., Stack, B. D., Symcox, E., . . . Lindsay, M. P. (2020). Canadian Stroke Best Practice Recommendations: Rehabilitation, Recovery, and Community Participation following Stroke. Part One: Rehabilitation and Recovery Following Stroke; 6th Edition Update 2019. *International journal of stroke*, *15*(7), 763-788. https://doi.org/10.1177/1747493019897843

Tempest, S., Harries, P., Kilbride, C., & De Souza, L. (2013). Enhanced clarity and holism: the outcome of implementing the ICF with an acute stroke multidisciplinary team in England. *Disability and Rehabilitation*, *35*(22), 1921-1925. https://doi.org/10.3109/09638288.2013.766272

The Commonwealth Fund. (2017). *2017 Commonwealth Fund International Health Policy Survey of Older Adults*. https://www.commonwealthfund.org/publications/surveys/2017/nov/2017-commonwealth-fund-international-health-policy-survey-older

The Intercollegiate Stroke Working Party. (2016). *National clinical guideline for stroke*. https://www.strokeguideline.org/

The Ministry of Health and Care Services. (2009). *Samhandlingsreforment -Rett behandling -på rett sted -til rett tid [The Coordination reform -The right treatment -in the right place -at the right time]*. The Ministry of Health and Care Services Retrieved from https://www.regjeringen.no/contentassets/d4f0e16ad32e4bbd8d8ab5c21445a5dc/no/pdfs/stm200820090047000dddpdfs.pdf

Forskrift om kommunal betaling for utskrivingsklare pasienter [Regulation regarding municipal payment for patients ready for discharge, (2011a). https://lovdata.no/dokument/SF/forskrift/2011-11-18-1115

The Ministry of Health and Care Services. (2011b). *Nevroplan 2015 [Neuroplan 2015]*. The Ministry of Health and Care Services Retrieved from https://www.regjeringen.no/contentassets/cca646be99be45af96eaec07a7739234/nevroplan2015.pdf?id=2291615

The Norwegian Directorate of Health. (2012). *Veileder for utvikling av kunnskapsbaserte retningslinjer [Guidance for development of evidence-based guidelines]*. Oslo: The Norwegian Directorate of Health Retrieved from https://www.helsedirektoratet.no/veiledere/utvikling-av-kunnskapsbaserte-retningslinjer/Veileder%20for%20utvikling%20av%20kunnskapsbaserte%20retningslinjer%20(fullversjon).pdf

The Norwegian Directorate of Health. (2017). *Nasjonal faglig retningslinje for behandling og rehabilitering ved hjerneslag. [National guidelines for treatment and rehabilitation in stroke]*. Oslo: The Norwegian Directorate of Health Retrieved from https://helsedirektoratet.no/retningslinjer/hjerneslag

The Norwegian Directorate of Health. (2019). *Pakkeforløp hjerneslag [A National Patient Pathway for stroke]*. Oslo: The Norwegian Directorate of Health Retrieved from https://www.helsedirektoratet.no/nasjonale-forlop/hjerneslag

The Norwegian Directorate of Health. (2021). *Rehabilitering i spesialisthelsetjenesten 2016-2020 [Rehabilitation in secondary health care 2016-2020]*.

https://www.helsedirektoratet.no/rapporter/rehabilitering-i-spesialisthelsetjenesten-2016-2020/Rehabilitering%20i%20spesialisthelsetjenesten%202016-2020.pdf

The Norwegian Stroke Registry. (2022). *Årsrapport for 2021 [Annual Report for 2021]*. https://stolav.no/Documents/%C3%85rsrapport%20Norsk%20hjerneslagregister%202021.pdf

Thompson, E. (2007). *Mind in life: biology, phenomenology, and the sciences of mind*. The Belknap Press of Harvard University Press.

Thornquist, E. (2009). *Kommunikasjon : teoretiske perspektiver på praksis i helsetjenesten* (2. utg. ed.). Gyldendal akademisk.

Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation*, *25*(11-12), 596-601. https://doi.org/10.1080/0963828031000137108

Van Criekinge, T., Truijen, S., Schröder, J., Maebe, Z., Blanckaert, K., van der Waal, C., Vink, M., & Saeys, W. (2019). The effectiveness of trunk training on trunk control, sitting and standing balance and mobility post-stroke: a systematic review and meta-analysis. *Clinical Rehabilitation*, *33*(6), 992-1002. https://doi.org/10.1177/0269215519830159

van Vliet, P. M., Lincoln, N. B., & Foxall, A. (2005). Comparison of Bobath based and movement science based treatment for stroke: a randomised controlled trial. *Journal of Neurology, Neurosurgery &Psychiatry*, *76*(4), 503-508. https://doi.org/10.1136/jnnp.2004.040436

Verbeek, J. M., van Wegen, E., van Peppen, R., van der Wees, P. J., Heniks, E., Rietberg, M., & Kwakkel, G. (2014). What Is the Evidence for Physical Therapy Poststroke? A Systematic Review and Meta-Analysis. *PLoS One*, *9*(2), e87987-e87987. https://doi.org/10.1371/journal.pone.0087987

Verheyden, G., Vereeck, L., Truijen, S., Troch, M., Herregodts, I., Lafosse, C., Nieuwboer, A., & De Weerdt, W. (2006). Trunk performance after stroke and the relationship with balance, gait and functional ability. *Clinical Rehabilitation*, *20*(5), 451-458. https://doi.org/10.1191/0269215505cr955oa

Vieira, T. M., Lemos, T., Oliveira, L. A. S., Horsczaruk, C. H. R., Freitas, G. R., Tovar-Moll, F., & Rodrigues, E. C. (2019). Postural Muscle Unit Plasticity in Stroke Survivors: Altered Distribution of Gastrocnemius' Action Potentials. *Frontiers in Neurology*, *10*, 686-686. https://doi.org/10.3389/fneur.2019.00686

Viruega, H., & Gaviria, M. (2022). After 55 Years of Neurorehabilitation, What Is the Plan? *Brain sciences*, *12*(8), 982. https://doi.org/10.3390/brainsci12080982

Waehler, I. S., Saltvedt, I., Lydersen, S., Fure, B., Askim, T., Einstad, M. S., & Thingstad, P. (2021). Association between in-hospital frailty and health-related quality of life after stroke: the Nor-COAST study. *BMC Neurology*, *21*(1), 100-100. https://doi.org/10.1186/s12883-021-02128-5

Westerdahl, E. (2013). Physical Therapy Research in Professional Clinical Practice. *Journal of Novel Physiotherapies*, *3*, 158.

Wevers, L., van de Port, I., Vermue, M., Mead, G., & Kwakkel, G. (2009). Effects of Task-Oriented Circuit Class Training on Walking Competency After Stroke A Systematic Review. *Stroke*, *40*(7), 2450-2459. https://doi.org/10.1161/STROKEAHA.108.541946

Wiener, J., McIntyre, A., Janssen, S., Chow, J. T., Batey, C., & Teasell, R. (2019). Effectiveness of High-Intensity Interval Training for Fitness and Mobility Post Stroke: A Systematic Review. *PM&R*, *11*(8), 868-878. https://doi.org/10.1002/pmrj.12154

Williams, L. S., Weinberger, M., Harris, L. E., Clark, D. O., & Biller, J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, *30*(7), 1362-1369. https://doi.org/10.1161/01.str.30.7.1362

Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., Deruyter, F., Eng, J. J., Fisher, B., Harvey, R. L., Lang, C. E., MacKay-Lyons, M., Ottenbacher, K. J., Pugh, S., Reeves, M. J., Richards, L. G., Stiers, W., & Zorowitz, R. D. (2016). Guidelines for Adult Stroke Rehabilitation and Recovery: A Guideline for Healthcare Professionals From the American

Heart Association/American Stroke Association. *Stroke*, *47*(6), e98-e169. https://doi.org/10.1161/STR.0000000000000098

Wittrup-Jensen, K. U., Lauridsen, J., Gudex, C., & Pedersen, K. M. (2009). Generation of a Danish TTO value set for EQ-5D health states. *Scandinavian journal of public health*, *37*(5), 459-466. https://doi.org/10.1177/1403494809105287

World Confederation for Physiotherapy. (2019). Policy Statement: Description of physical therapy. https://world.physio/sites/default/files/2020-07/PS-2019-Description-of-physical-therapy.pdf

World Health Organization. (2001). *International classification of functioning, disability and health : ICF*. World Health Organization.

World Health Organization. (2013). *How to use the ICF: A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF)*. World Health Organization.

World Health Organization. (2017). *Rehabilitation in health systems*. World Health Organization.

World Health Organization. (2018). *ICD 11*. Zurich, Switzerland: World Health Organization

Xie, J., Wu, E. Q., Zheng, Z.-J., Croft, J. B., Greenlund, K. J., Mensah, G. A., & Labarthe, D. R. (2006). Impact of stroke on health-related quality of life in the noninstitutionalized population in the United States. *Stroke*, *37*(10), 2567-2572. https://doi.org/10.1161/01.STR.0000240506.34616.10

Xing, Y., & Bai, Y. (2020). A Review of Exercise-Induced Neuroplasticity in Ischemic Stroke: Pathology and Mechanisms. *Molecular neurobiology*, *57*(10), 4218-4231. https://doi.org/10.1007/s12035-020-02021-1

Yew, K. S., & Cheng, E. (2009). Acute stroke diagnosis. *American Family Physician*, *80*(1), 33-40. https://www.aafp.org/pubs/afp/issues/2009/0701/p33.html

Zheng, S., & Yao, B. (2019). Impact of risk factors for recurrence after the first ischemic stroke in adults: A systematic review and meta-analysis. *Journal of Clinical Neuroscience*, *60*, 24-30. https://doi.org/10.1016/j.jocn.2018.10.026

Zhou, Q., Yang, H., Zhou, Q., & Pan, H. (2021). Effects of cognitive motor dual-task training on stroke patients: A RCT-based meta-analysis. *Journal of Clinical Neuroscience*, *92*, 175-182. https://doi.org/10.1016/j.jocn.2021.08.009

Aadland, E., & Ylvisaker, E. (2015). Reliability of the Actigraph GT3X+Accelerometer in Adults under Free-Living Conditions. *PLoS One*, *10*(8), e0134606-e0134606. https://doi.org/10.1371/journal.pone.0134606

Papers I - III

Paper I

Sivertsen, M., Arntzen, E. C., Alstadhaug, K. B., & Normann, B. (2022). Effect of innovative vs. usual care physical therapy in subacute rehabilitation after stroke. A multicenter randomized controlled trial. *Frontiers in rehabilitation sciences*, *3*, 987601. https://doi.org/10.3389/fresc.2022.987601

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 19 September 2022
DOI 10.3389/fresc.2022.987601

OPEN ACCESS

EDITED BY
Shih-Wei Huang,
Taipei Medical University, Taiwan

REVIEWED BY
Akhila Veerubhotla,
New York University, United States
Suruliraj Karthikbabu,
Kovai Medical Center Research and Educational Trust, India
Tamaya Van Criekinge,
University of Antwerp, Belgium

*CORRESPONDENCE
Marianne Sivertsen
marianne.sivertsen2@nordlandssykehuset.no

SPECIALTY SECTION
This article was submitted to Rehabilitation in Neurological Conditions, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 06 July 2022
ACCEPTED 30 August 2022
PUBLISHED 19 September 2022

CITATION
Sivertsen M, Arntzen EC, Alstadhaug Karl Bjørnar and Normann B (2022) Effect of innovative vs. usual care physical therapy in subacute rehabilitation after stroke. A multicenter randomized controlled trial.
Front. Rehabilit. Sci. 3:987601.
doi: 10.3389/fresc.2022.987601

Effect of innovative vs. usual care physical therapy in subacute rehabilitation after stroke. A multicenter randomized controlled trial

Marianne Sivertsen[1,2]*, Ellen Christin Arntzen[2,3],
Karl Bjørnar Alstadhaug[2,4] and Britt Normann[2,3]

[1]Department of Health and Care Sciences, UiT The Arctic University of Norway, Tromsoe, Norway, [2]Department of Medicine, Nordland Hospital Trust, Bodoe, Norway, [3]Faculty of Nursing and Health Sciences, Nord University, Bodoe, Norway, [4]Department of Clinical Medicine, UiT The Arctic University of Norway, Tromsoe, Norway

Background: Research on stroke rehabilitation often addresses common difficulties such as gait, balance or physical activity separately, a fragmentation contrasting the complexity in clinical practice. Interventions aiming for recovery are needed. The purpose of this study was to investigate effects of a comprehensive low-cost physical therapy intervention, I-CoreDIST, vs. usual care on postural control, balance, physical activity, gait and health related quality of life during the first 12 weeks post-stroke.

Methods: This prospective, assessor-masked randomized controlled trial included 60 participants from two stroke units in Norway. Participants, who were randomized to I-CoreDIST ($n = 29$) or usual care physical therapy ($n = 31$), received 5 sessions/week when in-patients or 3 sessions/week as out-patients. Primary outcomes were the Trunk Impairment Scale-modified Norwegian version (TISmodNV) and activity monitoring (ActiGraphsWgt3X-BT). Secondary outcomes were the Postural Assessment Scale for Stroke, MiniBesTEST, 10-meter walk test, 2-minute walk test, force-platform measurements and EQ5D-3L. Stroke specific quality of life scale was administered at 12 weeks. Linear regression and non-parametric tests were used for statistical analysis.

Results: Five participants were excluded and seven lost to follow-up, leaving 48 participants in the intention-to-treat analysis. There were no significant between-group effects for primary outcomes: TIS-modNV ($p = 0{,}857$); daily average minutes of sedative ($p = 0.662$), light ($p = 0.544$) or moderate activity ($p = 0.239$) and steps ($p = 0.288$), or secondary outcomes at 12 weeks except for significant improvements on EQ5D-3L in the usual care group. Within-group changes were significant for all outcomes in both groups except for activity levels that were low, EQ5D-3L favoring the usual care group, and force-platform data favoring the intervention group.

Conclusions: Physical therapy treatment with I-CoreDIST improved postural control, balance, physical activity and gait during the first 12 weeks after a stroke but is not superior to usual care.

KEYWORDS

physical therapy, stroke, rehabilitation, trunk control, balance, gait, physical activity, health related quality of life

Introduction

Stroke is a common cause of physical and cognitive disabilities. It is associated with lower levels of health-related quality of life (HRQOL) (1) and low levels of physical activity both during in-patient rehabilitation (2, 3) and in the long term (4, 5). Physical therapy is integral to the rehabilitation chain after a stroke, and is effective in reducing the burden of disability (6, 7). Strong evidence exists to support that increased dose and intensity of physical therapy increase functional gains (6). Recommendations, however, are often not achieved.

Research on stroke rehabilitation often addresses either gait, balance or upper limb function or specific treatments targeting single impairments (8). This fragmentation in research is in contrast to the complexity encountered by physical therapists in clinical stroke rehabilitation (9, 10), where the patients' movement problem often constitutes a combination of impairments and their mutual influence on each other. The main aims of physical therapy after a stroke are to improve walking, balance and functional movement (6), for which trunk control is a prerequisite (11–13). Reduced trunk control is common after a stroke and often persists into the sub-acute and chronic phases (12, 13). Such dysfunction is associated with poor functional mobility, reduced independence in activities of daily living and increased risk of falls (13–15). Recent reviews have concluded that there is evidence to support that trunk control, sitting and standing balance and mobility may significantly improve following trunk training after a stroke (13, 16–18). Findings support intensive rehabilitation treatment targeting trunk control to regain mobility and gait early after a stroke (14). The examined effect of trunk training is often in addition to usual care, thus separating the training of trunk control from the training of functional tasks, balance and gait. In daily activities these are inextricably linked, for example through the fine adjusted timing of anticipatory postural adjustments, that occur prior to the center of mass displacements associated with movements (19). The timing and symmetry of anticipatory postural adjustments are often affected after a stroke (20). There is a need to investigate if integrating trunk training and usual care could lead to greater functional gains.

New interventions in stroke rehabilitation should comprise clearly defined evidence (Langhorne 2009) and science-based methods (Nielsen 2015), and should aim to enhance recovery as opposed to compensatory strategies (21, 22). I-CoreDIST[1] (**Table 1**) is a comprehensive, innovative rehabilitation method where activation of core muscles is enhanced and integral to all exercises without compromising focus on functional tasks or intensity. We support Kibler's (23) definition of core stability as "the ability to control the position and motion of the trunk over the pelvis and leg to allow optimum production, transfer and control of force and motion to the terminal segment in integrated kinetic chain activities", (p. 190). This view incorporates an extended perspective of core muscles as all muscles on the trunk and those attached to the trunk, thus including muscles on the shoulder and hip girdle. The novelty of this approach lies within its integration of core muscle activation into exercises that incorporate functional activities, muscle strength, active muscle lengthening, upper limb function, gait and endurance. The structured assessment, clinical reasoning aids and the variation of exercises ensures individual tailoring and specificity. I-CoreDIST is designed to follow the patient through the course of rehabilitation, thus addressing fragmentation of care delivery and lack of continuity between care centers, a recognized barrier to recovery in stroke rehabilitation (9, 24, 25). The implementation of I-CoreDIST in the sub-acute stage after a stroke has successfully been explored in a non-controlled pilot study that demonstrated significant improvements in balance, postural control, walking-speed and -distance from baseline to 4 and 12 weeks (26).

The purpose of this study was to investigate the effect of I-CoreDIST when implemented in sub-acute, post-stroke physical therapy by addressing the following research question: Is physical therapy with I-CoreDIST better at improving postural control, levels of physical activity, balance, gait and HRQOL than usual care physical therapy when implemented during the first 12 weeks after a stroke.

Materials and methods

Trial design

This assessor-blinded, two arm parallel group, randomized controlled trial (RCT) was registered at ClinicalTrials.gov (ClinicalTrials.gov Identifier: NCT04069767) prior to inclusion of participants. The study adhered to the CONSORT guidelines and to guidelines for data protection set by the involved institutions.

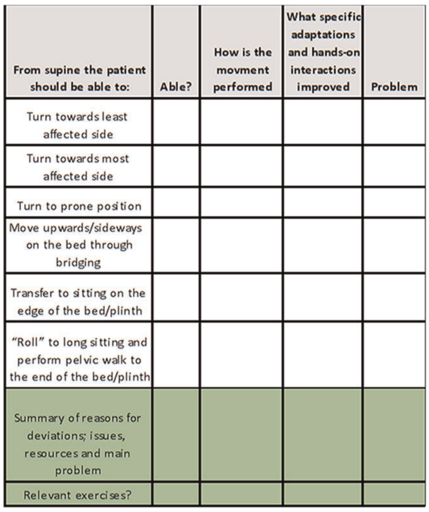
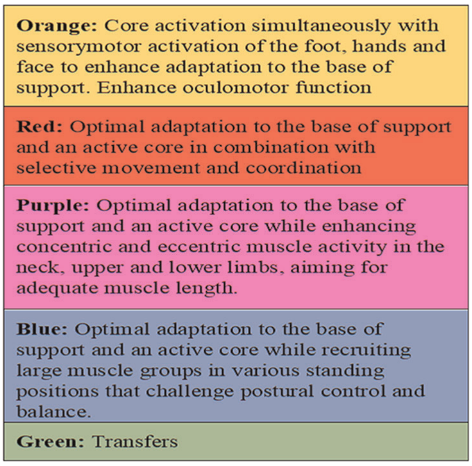
Ethics

The study was approved by the Regional Committee of Medical and Health Research Ethics (REK North: 2017/1961)

---

[1] I-CoreDIST: I = individualised, Core = trunk, D = dual task, I = intensive, S = specific, stability, somatosensory stimulation, T = teaching, training. Individualised Core activation combined with DISTal functional movement

TABLE 1 Outline of the I-core DIST intervention.

Main Features	Assessment	Exercises
Common features in all exercises are enhancement of dynamic trunk stability and functional movements, combined with the following: Optimized alignment and adaptation to the base of support and often using an unstable reference point for the trunk (therapeutic ball) or the distal body parts. Enhanced somatosensory integration of hands, feet and face, including reduced influence of vision to enhance somatosensory integration. Proximal stability prior to selective task-oriented movement of limbs, head, eyes. Inclusion of dual tasks (motor/motor and motor/cognitive) in exercises and activities such as walking indoors, out-doors and climbing stairs. Specific hands-on interactions or other adaptations to optimize alignment and neuromuscular recruitment. Exercises combining core activation and increase in heart rate: in lying, sitting, standing and walking.	• History • General function • Specific assessment • Exploration of possibilities for change • Conclusions • Goals • Clinical reasoning charts for assistance • Example of clinical reasoning chart: 	44 exercises, each with five levels of difficulty and choices of starting positions: • Supine • Side-lying • Prone • Sitting • Standing • Stepping and walking. All individual exercises have been assigned a color, indicating the main aims: 

From supine the patient should be able to:	Able?	How is the movment performed	What specific adaptations and hands-on interactions improved	Problem
Turn towards least affected side				
Turn towards most affected side				
Turn to prone position				
Move upwards/sideways on the bed through bridging				
Transfer to sitting on the edge of the bed/plinth				
"Roll" to long sitting and perform pelvic walk to the end of the bed/plinth				
Summary of reasons for deviations; issues, resources and main problem				
Relevant exercises?				

Orange: Core activation simultaneously with sensorymotor activation of the foot, hands and face to enhance adaptation to the base of support. Enhance oculomotor function

Red: Optimal adaptation to the base of support and an active core in combination with selective movement and coordination

Purple: Optimal adaptation to the base of support and an active core while enhancing concentric and eccentric muscle activity in the neck, upper and lower limbs, aiming for adequate muscle length.

Blue: Optimal adaptation to the base of support and an active core while recruiting large muscle groups in various standing positions that challenge postural control and balance.

Green: Transfers

and complies with the Declaration of Helsinki. All participants provided written informed consent prior to inclusion. The funders played no role in the design, conduct or reporting of this study.

Context of the study

The study was conducted in collaboration with two hospitals in two regions of Norway, two rehabilitation units and six surrounding municipalities. Participants were recruited at the hospitals stroke units where they underwent baseline testing prior to discharge and a follow-up assessment after 12 weeks. Inclusion started in September 2019 and ended in December 2021. Due to lockdown and subsequent restrictions related to the Covid-19 pandemic, inclusion and physiotherapy treatment for already included participants were stopped between March and June 2020.

Participants

Eligible participants, aged 18–85, had to be admitted to one of the two stroke units with a confirmed new stroke, have a premorbid modified Ranking Scale (mRS) of 0–3, be able to sit for 10 s at baseline testing, and to have a Trunk Impairment Scale-modified Norwegian version (TIS-modNv) score of <15. Exclusion criteria were inability to cooperate in physical therapy, ongoing substance abuse, severe disease, known dementia or other mental or cognitive disability preventing participation in physical therapy. After inclusion a baseline-assessment, evaluating trunk control, balance and gait along with self-administered questionnaire on health-related quality of life, was administered.

Randomization

After baseline assessment, the participants were randomly assigned to one of two trial arms, A and B, in a 1:1 ratio. Randomization was stratified into two groups based on functional disability at baseline defined by mRS < 4 or ≥4 to minimize selection bias and to preserve homogeneity between arms. A digital solution, RedCap (Research Electronic Data Capture) tools hosted at the Northern Norway Regional Health Authority was used for randomization and data collection. Randomization was performed by an investigator, not connected to assessment or treatment of the patients, who informed the relevant physical therapist at rehabilitation units and/or municipalities of group allocation. The participants and the outcome assessors were blinded to group allocation.

Interventions, I-CoreDIST and usual care

The flow of patients through the study is summarized in **Figure 1**. The intervention period commenced after discharge from the stroke unit and lasted through the patient's individual rehabilitation course for 12 weeks. Time of and destination at discharge were not affected by participation in the study. Each physical therapy session lasted 60 min and was performed 5–6 days/per week if in a rehabilitation unit, and 3 sessions/week if in home based or outpatient treatment. Both groups received equal doses of physical therapy. Written reports followed the patient throughout the rehabilitation chain along with medical and multidisciplinary care as usual. Registrations of frequency and content of I-CoreDIST and usual care sessions were recorded for 12 weeks by the physical therapists.

I-CoreDIST

The principles behind the I-CoreDIST intervention is outlined in **Table 1**. In I-CoreDIST structured core muscle activation is actively incorporated into exercises that simultaneously demand muscle strength, active muscle lengthening and endurance. These exercises specifically aim to improve, balance, gait, transfers upper limb function and functional activities, thus enhancing the training of the specific aspects of trunk function needed in everyday activities. The intervention started with an assessment to identify the patient's movement problems, supported by clinical reasoning charts, and contains 44 exercises, each with five levels of difficulty to allow for specificity and individualization. All physical therapists who treated participants in the I-CoreDIST group received 45 h of training prior to commencement of the study, one follow-up day during inclusion, and an educational package containing (1) the theoretical rationale behind the approach, (2) assessment and clinical reasoning charts and (3) images and descriptions of all exercises (**Figures 2–4**).

Usual care

There were no guidelines regarding the content of physical therapy, each individual therapist made treatment choices according to existing guidelines and what was usually offered to this patient group in that particular institution or municipality. The content of usual care in clinical practice in Norway is highly variable and poorly documented. Approaches towards stroke rehabilitation vary between the different schools of physiotherapy and traditions within institutions and municipalities. The Norwegian guidelines for treatment and rehabilitation after a stroke provide only general advice on including; intensive task related training containing a strength component for patients with paresis, training of transfers, gait and cardiovascular fitness, bilateral or constraint induced arm training (27). Specific training of trunk control is not a part of the recommendation for rehabilitation of sensorimotor disturbances after a stroke (27), but is part of the treatment tradition in some institutions.

Outcome measures

The primary outcomes were trunk control, evaluated by TIS-modNV and physical activity, measured by an accelerometer and quantified into sedentary time, time in light, moderate and vigorous activity and number of steps. TIS-modNV is a 0–16-point scale, for which the ability to sit without support for 10 s is a prerequisite. It is considered a valuable tool for evaluation of trunk control and The scale has been proven reliable (ICC = 0.85) and valid for the stroke population (28), is sensitive, and do not have a ceiling effect.The minimal detectable change (MDC) is 2.9 points (28). ActiGraph Wgt3X-BT (ActiGraph, LCC, Pensacola, United States) is a 3-axis accelerometer used to record physical activity. It has been proven reliable in an adult population (29) and valid (ICC = 0.70) for use in the stroke population (30). Levels of physical activities are reflective of recovery of the activity limitation often experienced by stroke patients (31). The participants were instructed to wear the activity monitor in a waistband 24 h/day for seven consecutive days, after both baseline testing and the 12-week follow-up assessment. The participants were instructed to remove the device during showers/baths only. The devices were initialized and data were downloaded using ActiLife Software (ActiGraph, LCC, Pensacola, United States). Data were collected at a frequency of 100 Hz.

Secondary outcomes were postural control, balance, gait speed and distance, and HRQOL. We used the Swedish Postural Assessment Scale for stroke -Norwegian Version (SwePASS-NV) to measure postural control and the ability to maintain equilibrium during positional changes. It is sensitive for assessment of postural control after a stroke, and has excellent validity ($\alpha = 0.99$, $p < 0.001$) (32), and reliability ($ICC \geq 0.99$) (33). The scale ranges from 0 to 36 and has a ceiling, but no floor effect. The MDC in subacute stroke is 2.2 points (34). MiniBESTest was used to measure pro-and reactive balance in standing and walking on a scale from 0 to 28. It has a floor effect, as participants must be able to stand without support. The Norwegian version has shown good reliability (ICC = 0.95) and validity (35). The MDC for MiniBESTest is 3.2 points. In addition, the minimal clinically

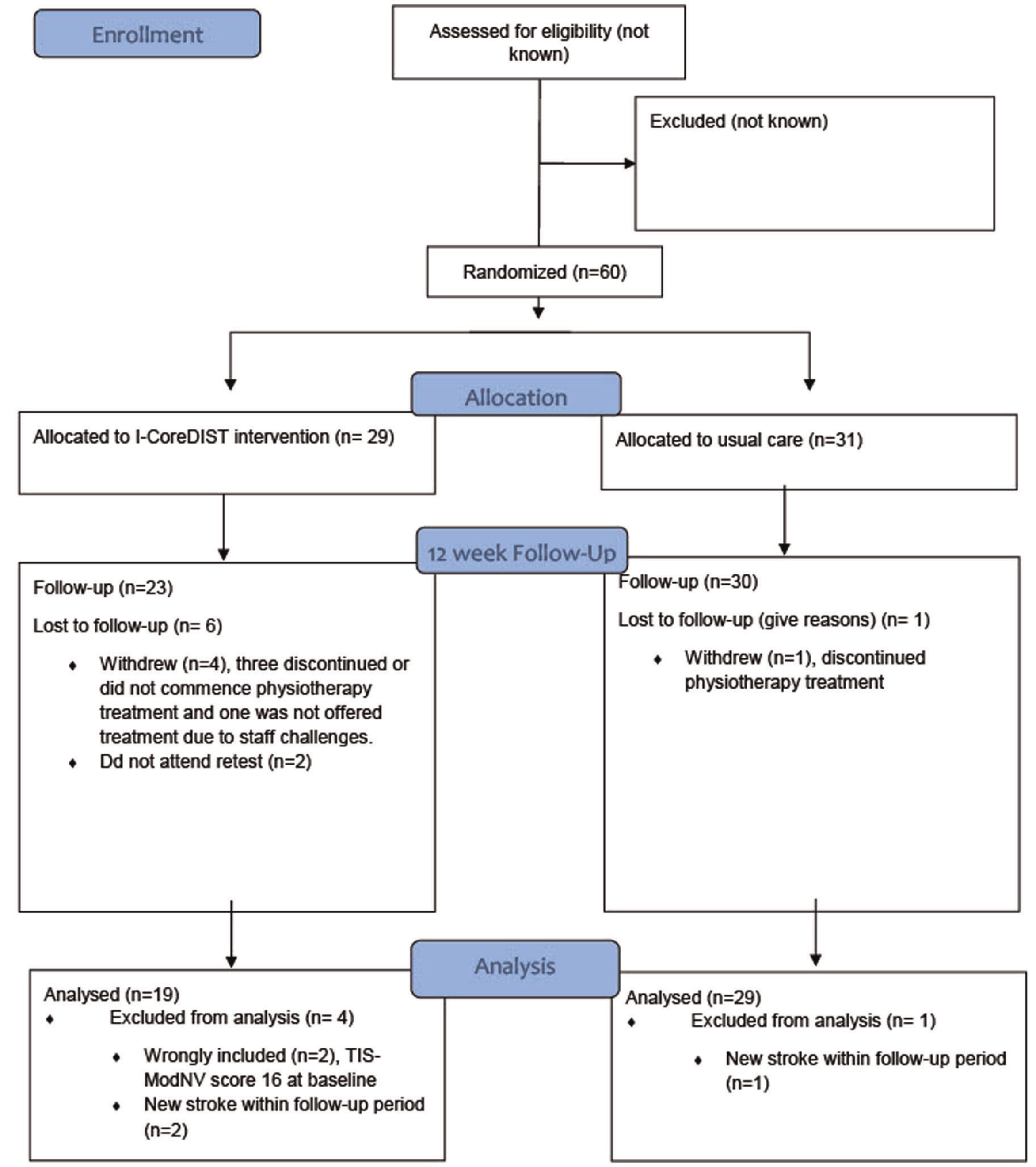


FIGURE 1
The flow of patients through the study.

important difference (MCID) for detecting small changes is 4 points and five points for detecting substantial changes (36). Stability during quiet stance was assessed by calculating sway amplitude using AMTI AccuGait Optimized™ (Advanced Mechanical technology, Inc., Watertown, United States) multi-axis force plate system. Data on center of pressure (COP) displacements in cm were collected for 30 s with a frequency of 50 Hz (37) in the domains of eyes open and eyes closed and root mean square (RMS) values of the COP displacements were calculated. Reliability has been established for measuring COP displacements during quiet stance in the anteroposterior (AP) (ICC = 0.77) and mediolateral (ML) (ICC = 0.74) directions in a stroke population (38). Participants who were able to walk with or without an aid

The yes

Aim: Active and stable core in combination with activating deep neck flexors and active shortening and lengthening of lateral trunk muscles.

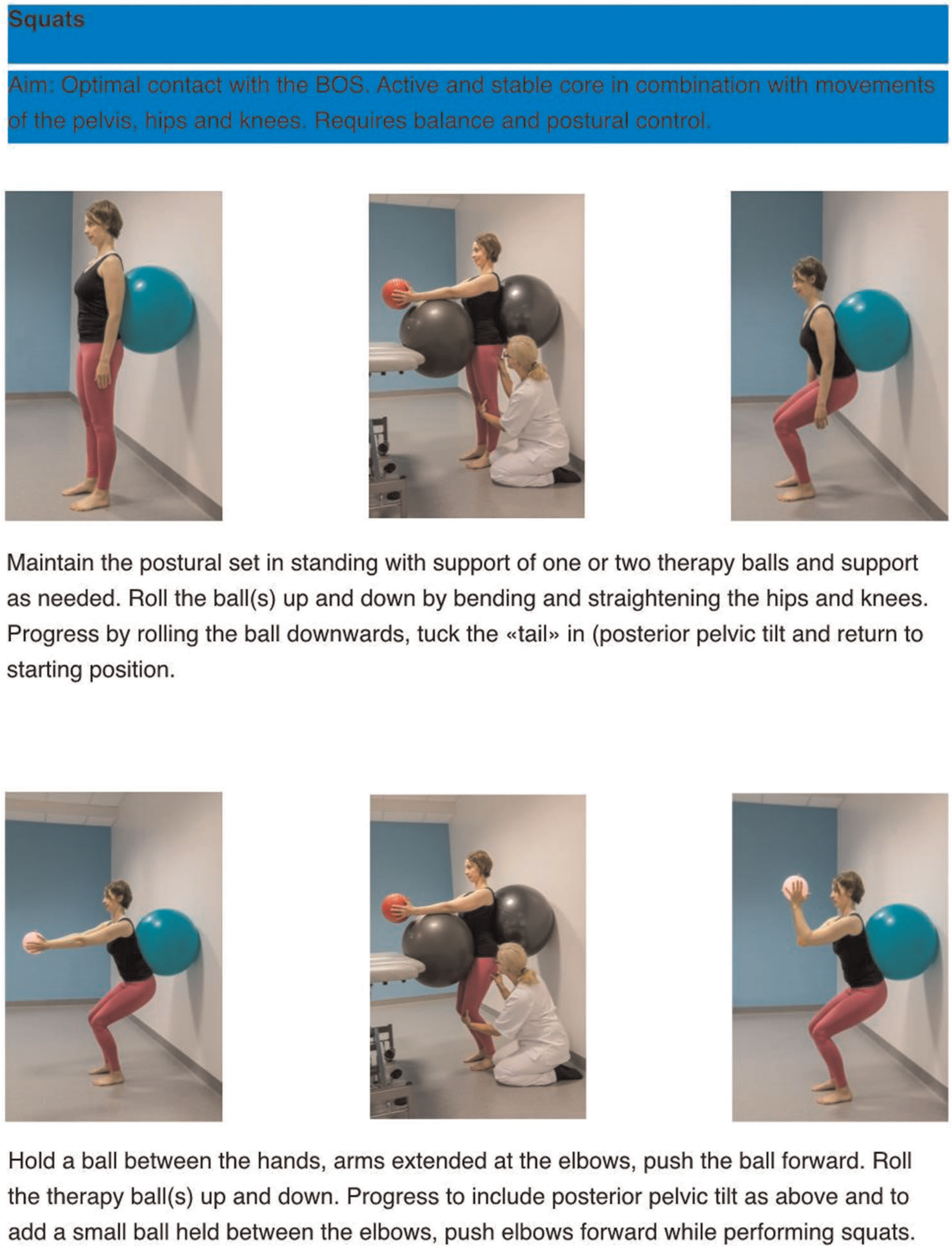
Perform a nodding movement, as if saying «yes» by tucking the chin in and elongating the back of the neck. Core activation may be enhanced by providing hands on facilitation.

Maintain the postural set with the chin tucked in and roll the therapy ball from side to side using your upper body.

Hold a small ball between the palms of your hands with extended arms in about 45 degrees flexion at the shoulders, Look at the ball and tuck in the chin to maintain an elongated posterior neck. Further progressions may include trowing and catching a ball, towel, balloon, incorporating gaze stability excercises etc.

FIGURE 2
Example of exercise aiming for optimal adaptation to the base of support, an active core as well as enhancement of concentric and eccentric mucle activity in the neck.

performed: (1) 10-Meter Walk Test (10 MWT), measuring walking speed (meters/s) at preferred and fast paces, reliable (ICC = 0.76) and valid for use in the stroke population (39, 40). MCID for 10 MWT preferred pace is 0.16 m/s (41) and 0.13 m/s for the 10 MWT fast pace (42) and (2) The 2-Minute Walk Test (2 MWT), measuring the total distance walked in two minutes, conducted on a 20 m walkway, also reliable (ICC = 0.85) for the stroke population (43). For non-ambulant participants, 0 meter/s was recorded at baseline or 12 weeks. HRQOL was reported using EQ-5D-3L and the stroke specific quality of life scale (SSQOL). EQ-5D-3L is a questionnaire used to assess self-perceived HRQOL, comprising five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, each with three levels of response, and a VAS scale (0–100) recording perceived health (44). EQ5D-3L has been proven reliable and



Squats

Aim: Optimal contact with the BOS. Active and stable core in combination with movements of the pelvis, hips and knees. Requires balance and postural control.

Maintain the postural set in standing with support of one or two therapy balls and support as needed. Roll the ball(s) up and down by bending and straightening the hips and knees. Progress by rolling the ball downwards, tuck the «tail» in (posterior pelvic tilt and return to starting position.

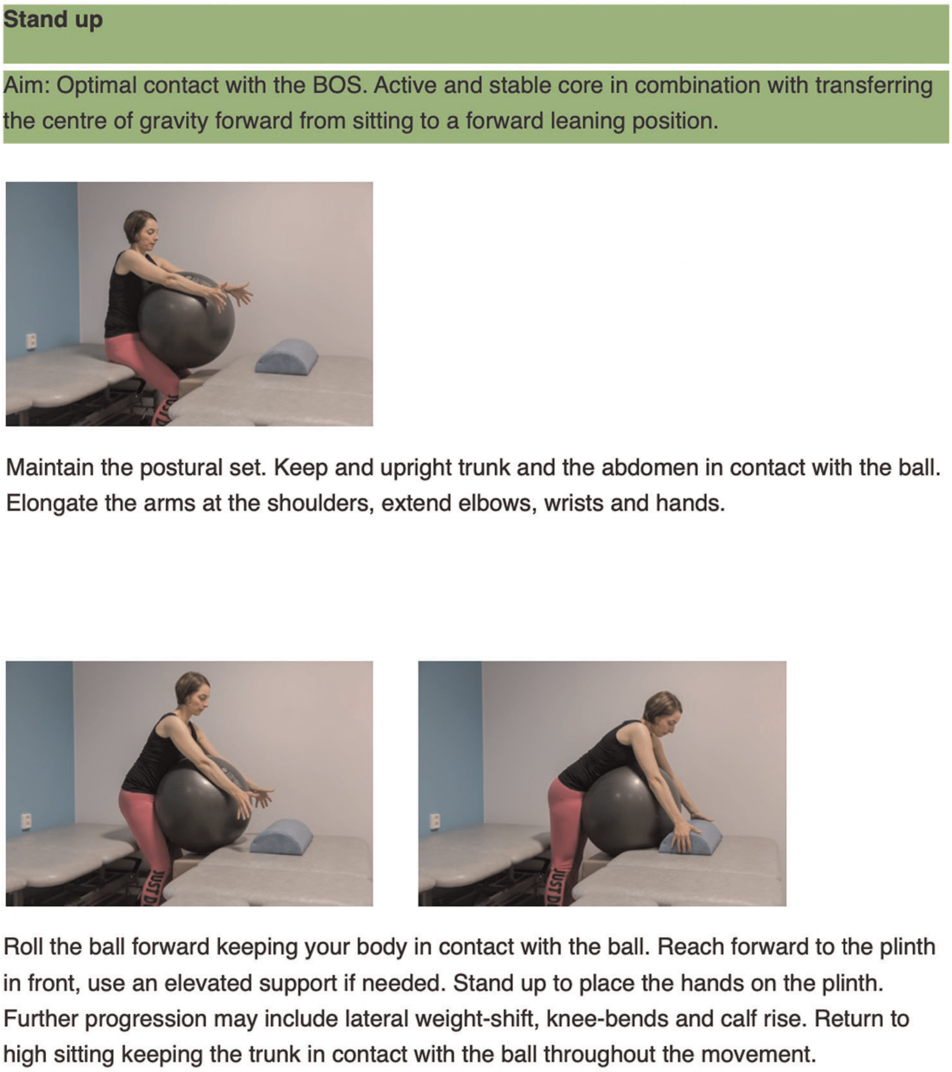
Hold a ball between the hands, arms extended at the elbows, push the ball forward. Roll the therapy ball(s) up and down. Progress to include posterior pelvic tilt as above and to add a small ball held between the elbows, push elbows forward while performing squats.

FIGURE 3
Example of exercise aiming for optimal adaptation to the base of support, an active core, activity in large muscle groups in a standing position while challenging postural control and balance.

valid for use in a stroke population (45, 46). SSQOL assesses health-related quality of life specific for stroke survivors. It is a 49-item questionnaire, addressing 12 domains: self-care, vision, language, mobility, work/productivity, upper extremity function, thinking, personality, mood, family roles, social roles and energy (47). The Norwegian translation has shown excellent reliability (ICC = 0.97) and validity (48). SSQOL was administered only at 12 weeks retest as it was not considered appropriate in the acute stage.

Sample size

Sample size was calculated based on the mean and standard deviation of TIS-modNV-scores from a preceding pilot study (26). A difference of 0.67 standard deviation (SD) (1.93 points) between the intervention and the control group was considered clinically relevant. Thirty-seven individuals in each group were required to obtain an 80% chance to detect a difference of 1.93 points on TIS-modNV



Stand up

Aim: Optimal contact with the BOS. Active and stable core in combination with transferring the centre of gravity forward from sitting to a forward leaning position.

Maintain the postural set. Keep and upright trunk and the abdomen in contact with the ball. Elongate the arms at the shoulders, extend elbows, wrists and hands.

Roll the ball forward keeping your body in contact with the ball. Reach forward to the plinth in front, use an elevated support if needed. Stand up to place the hands on the plinth. Further progression may include lateral weight-shift, knee-bends and calf rise. Return to high sitting keeping the trunk in contact with the ball throughout the movement.

FIGURE 4
Example of exercise that aim for optimal adaptation to the base of support, an active core while practicing transferring the centre of gravity forward as in a sit to stand transfer.

between the groups with a significance level of 0.05 (alpha) on two-sided tests.

Data analysis

Prior to statistical analysis the COP data were filtered using a fourth order Butterworth filter applied at 10 Hz (49) using BalanceClinic software (AMTI). The raw COP-data were imported to MatLab (Mathworks, Natick, MA, United States) where average RMS-values of COP-displacements in the AP (COPy) and ML (COPx) planes were calculated using the formula $\text{RMS AP} = \sqrt{\frac{1}{n}(y_1^2 + y_2^2 + y_n^2)}$, and $\text{RMS ML} = \sqrt{\frac{1}{n}(x_1^2 + x_2^2 + x_n^2)}$. Raw activity data were converted into daily average minutes of sedative time, light, moderate and vigorous activity using the ActiLife Software (ActiGraph, LCC, Pensacola, United States). Data were downloaded for all days, but day 1 and 8 were excluded due to differences in starting time. EQ5D profiles were summarized by calculating index values for each respondent (50). We utilized the value set from Denmark (51) as there is no available sets for Norway. This value set has previously been utilized in a Norwegian stroke population (52). Index values were also calculated for the SSQOL-data, converting scores from the 49 individual items

TABLE 2 Demographic data.

Baseline characteristics	Intervention group ($n = 25$)	Control group ($n = 30$)	p
Age: mean (SD)	72.96 (10.41)	69.32 (10.63)	0.17
Gender			
Male, n (%)	12 (48)	23 (76.66)	
Female, n (%)	13 (52)	7 (23.33)	
Cohabiting, n (%)	17 (68)	21 (70)	
Premorbid mRS mean (SD) (inclusion criteria: mRS < 4)	0.83 (1.09)	0.46 (0.15)	0.12
Type of stroke			
Infarction, n (%)	24 (96)	26 (86.66)	
Hemmorage, n (%)	1 (4)	4 (13.33)	
Stroke location			
Right hemisphere, n (%)	11 (44)	15 (50)	
Left hemisphere, n (%)	10 (40	14 (46.7)	
Bilateral, n (%)	4 (16)	1 (3.3)	
NIHSS score at admission: mean (SD)	5.04 (1.08)	3.64 (0.58)	0.22
Barthel Index admission: mean (SD)	82.29 (26.33)	81.07 (21.14)	0.85
Previous stroke, n (%)	7 (28)	6 (20)	

into average scores for the 12 domains. Missing data were handled using person mean imputation and replaced by the domain average if one missing in a three-question domain or two missing in a five/six question domain. Forms were discarded if more than five missing items.

Statistical analysis

We performed an intention-to-treat analysis. Continuous variables are presented as means and standard deviations (SD) or median and interquartile range (IQR) depending on normality distribution. Categorical variables are presented as numbers and percentages. A multiple linear regression model was used to test if group allocation significantly predicted 12-week retest score when adjusting for baseline scores. If the data violated the assumptions for linear regression analysis, we performed a natural log transformation or used a Mann-Whitney U test for between-group differences. Within-group differences were calculated using paired samples t-test given a normal distribution of data and Wilcoxon signed rank test if not. Significance level was set at $p < 0.05$. All analyses were carried out using IBM SPSS (Statistics version 27 SPSS INC., Chicago IL).

Results

A total of 60 participants were recruited between September 2019 and September 2021. Baseline characteristics are outlined in Table 2. Twentynine participants were randomized to the intervention group (I-CoreDIST) and 31 to the usual care group (Figure 1). The groups did not significantly differ in baseline characteristics, but there was a trend towards higher mean age ($p = 0.17$), lower premorbid levels of function (mRS) ($p = 0.12$) and higher scores for stroke severity on the NIH Stroke Scale (NIHSS) ($p = 0.22$) in the intervention group. The intervention group also had a higher rate of bilateral strokes, while the control group had a higher rate of hemorrhagic strokes. In the intervention group, six participants were lost to follow-up and another four were excluded from analysis. In the usual care group, one was lost to follow-up and one was excluded from analysis (Figure 1).

We used a multiple linear regression model for TIS-modNV, SwePASS-NV, MiniBesTEST, 10 MWT preferred and fast paces, activity data and 2 MWT and EQ5D-3L-scores (Table 3). There were some missing activity data at baseline as four monitors were not returned. In addition, three were excluded from analysis due to faulty monitors or a lack of registered activity in bouts exceeding that presumed to be inactivity. At retest, 15 participants did not attend or did not return the monitor, one was excluded due to little wear-time. Data in the categories of average minutes of moderate activity and average number of steps per day were skewed, thus natural log transformation were performed. The fitted regression model was a poor fit for the force platform data even after log transformation and as a result non-parametric tests were used to determine between-group differences.

Group allocation was not a significant predictor of 12-week retest score when adjusted for baseline differences for the primary outcomes TIS-modNV ($p = 0.857$), or for the activity data across all categories: Sedative minutes/day ($p = 0.228$), minutes of light activity/day ($p = 0.155$), minutes of moderate activity/day ($p = 0.127$), average number of steps/day ($p = 0.887$) (Table 3). Paired samples t-tests revealed significant within-group changes for TIS-modNV ($p < 0.001$) in both groups (Table 4) and Wilcoxons signed rank test showed significant within group changes in favor of the usual care group in the categories “minutes of moderate activity” per day ($p = 0.005$) and “average number of steps/day” ($p = 0.042$) for the activity data. There was a trend towards lower p-values for the intervention group regarding reduction in sedative minutes/day and increase in minutes of light activity/day (Table 4).

For the secondary outcome measures, the regression model and Mann-Whitney U test showed no significant differences between groups at 12-week retest (Tables 3, 5), except for EQ5D-3L-scores where group allocation significantly predicted 12-week retest scores in favor of the usual care group ($p = 0.003$) (Table 3). There were significant within-group changes in both groups on MiniBesTest ($p < 0.001$), 10 MWT at preferred pace (intervention group: $p = 0.007$, usual care group $p < 0.001$), SwePASS-NV (Intervention group: $p = 0.001$, usual care group $p < 0.001$) and 2 MWT (intervention group: $p = 0.01$,

TABLE 3 Regression model.

Outcome measure	ANOVA				Coefficients				
	R^2	$F(2,45)$	p		B	95% CI	β	t	p
Primary									
TIS-modNv	0.37	39.64	<0.001	Constant	4.81	2.39, 7.24		3.99	<0.001
				Group allocation	−0.14	−1.38, 1.16	−0.02	−0.18	0.86
				Baseline score	0.75	0.58, 0.92	0.80	8.90	<0.001
Activity data									
Sed mins/day	0.21	4.43	0.02	Constant	672.02	281.60, 1062.44		3.50	0.001
				Group allocation	38.90	−25.47, 103.27	0.19	1.23	0.23
				Baseline score	0.39	0.09, 0.69	0.41	2.66	0.01
Light mins/day	0.21	4.42	0.02	Constant	206.11	90.47, 321.75		3.63	0.001
				Group allocation	−43.66	−104.65, 17.33	−0.23	−1.46	0.16
				Baseline score	0.37	0.08, 0.67	0.40	2.56	0.02
Mod mins/day*	0.33	7.33	0.003	Constant	0.19	−1.18, 1.57		0.29	0.78
				Group allocation	0.59	−0.18, 1.35	0.24	1.57	0.13
				Baseline score	0.56	0.25, 0.88	0.55	3.67	0.001
Steps/day*	0.21	4.47	0.02	Constant	4.50	2.19, 6.81		3.96	<0.001
				Group allocation	0.03	−0.48, 0.55	0.20	0.13	0.89
				Baseline score	0.44	0.14, 0.74	0.46	2.96	0.01
Secondary									
SwePASS-NV	0.60	33.19	<0.001	Constant	18.31	14.20, 22.45		8.98	<0.001
				Group allocation	−0.33	−1.62, 0.96	−0.05	−0.52	0.61
				Baseline score	0.5	0.38, 0.62	0.78	8.13	<0.001
MiniBesTEST	0.51	22.95	<0.001	Constant	9.87	4.80, 14.95		3.92	<0.001
				Group allocation	1.42	−1.34, 4.18	0.11	1.03	0.31
				Baseline score	0.52	0.36, 0.68	0.70	6.69	<0.001
10 MWT (m/s)	0.50	22.40	<0.001	Constant	0.56	0.34, 0.78		5.17	<0.001
				Group allocation	0.07	−0.05, 0.13	0.13	1.22	0.23
				Baseline score	0.43	0.29, 0.56	0.68	6.45	<0.001
10 MWT fast (m/s)	0.49	21.42	<0.001	Constant	0.58	0.21, 0.96		3.12	0.003
				Group allocation	0.16	−0.04, 0.37	0.17	1.62	0.11
				Baseline score	0.51	0.34, 0.67	0.67	6.28	<0.001
2 MWT (m)	0.53	25.26	<0.001	Constant	71.120	34.20, 108.04		3.88	<0.001
				Group allocation	12.282	−8.37, 32.93	0.12	1.20	0.24
				Baseline score	0.501	0.35, 0.69	0.71	6.85	<0.001
EQ5D index	0.55	21.08	<0.001	Constant	0.268	0.75, 0.46		2.83	0.01
				Group allocation	0.154	0.29, 0.60	0.37	3.20	0.003
				Baseline score	0.442	0.06, 0.25	0.66	5.74	<0.001

*Natural log transformations were performed.

usual care group $p \leq 0.001$). Only the usual care group showed significant improvements in 10 MWT fast pace ($p < 0.001$) and EQ5D ($p < 0.001$) at 12-week retest when compared to baseline (Table 4). Within-group changes for the force-platform data were significant in favor of the intervention group in the domain of COP_x with eyes open ($p = 0.05$) and COP_y with eyes open ($p = 0.01$) and eyes closed ($p = 0.03$) (Table 5).

Regarding the SSQOL, 43 forms were returned and 17 of these had missing data. Two were discarded due to two missing items in a three-question domain. Both groups shared similar trends with regards to which domains had the highest ("vision" and "self-care") or lowest ("energy") scores. The usual care group had higher median scores at 12 weeks in all domains, but "vision" where scores were equal (Table 6) and had a higher total index score at 12 weeks post stroke. Differences between groups were more pronounced in the cognitive-social-mental components than in the physical health components of the SSQOL (Figure 5). Mann-Whitney U test showed significant group differences in index scores, all favoring of the usual care group in the domains of "language" ($p = 0.005$), "mobility" ($p = 0.036$), "upper extremity function" ($p = 0.011$), thinking ($p = 0.011$), personality ($p = 0.019$) and mood ($p = 0.006$) domains.

The calculation of average number of weeks in physical therapy was based on the returned forms from the physical therapists (Supplementary Material). Participants in the intervention group: completed on average 7.94 (SD 3.45) weeks of physiotherapy. In the usual care group, the participants completed an average of 10.36 (SD 2.31) weeks of physiotherapy. Differences in how the forms were filled out made it difficult to determine the number of sessions completed by each participant.

TABLE 4 Within-group changes.

Primary outcome measures

Outcome	Group	Baseline Mean (SD)	12-week retest Mean (SD)	Change Mean difference 95%CI	Paired samples *t*-test *p*
TIS-Nv score	Intervention	7.37 (3.53)	10.21 (3.29)	2.84 1.85, 3.84	<0.001
	Usual care	7.79 (3.87)	10.41 (3.63)	2.62 1.69, 3.55	<0.001

Outcome Activity data	Group	Baseline Median [IQR]	12-week retest Median [IQR]	Change Median difference	Wilcoxon signed rank test *Z, p*
Sedative mins/day	Intervention	1,268 [152]	1,241 [189]	−27	−1.41, 0.16
	Usual care	1,270 [164]	1,263 [104]	−7	−0.83, 0.41
Light act mins/day	Intervention	163 [132]	199 [189]	36	−1.41, 0.16
	Usual care	157 [163]	164 [120]	7	−0.57, 0.57
Mod acti mins/day	Intervention	1 [13]	2.5 [8]	1,5	−0.27, 0.79
	Usual care	3 [5]	8 [26]	5	−2.84, 0.005
Vig act mins/day	Intervention	0 [0]	0 [0]	0	0, 1.0
	Usual care	0 [0]	0 [0]	0	0, 1.0
Steps/day	Intervention	1,723 [2,718]	2,099 [2,880]	376	−1.35, 0.18
	Usual care	1,575 [2,301]	3,327 [3,170]	1752	−2.03, 0.04

Secondary outcome measures

Outcome	Group	Baseline Mean (SD)	12-week retest Mean (SD)	Change Mean difference 95%CI	Paired samples *t*-test *p*
MiniBesTEST score	Intervention	13.47 (9.48)	18.32 (6.57)	4.84 2.22, 7.46	<0.001
	Usual care	13.65 (8.29)	19.83 (6.43)	6.17 3.63, 8.71	<0.001
10 mwt, (m/s)	Intervention	0.72 (0.47)	0.94 (0.30)	0.22 0.07, 0.37	0.007
	Usual care	0.80 (0.44)	1.05 (0.26)	0.24 0.12, 0.37	<0.001
10 mwt fast (m/s)	Intervention	1.05 (0.70)	1.28 (0.44)	0.23 −0.01, 0.47	0.06
	Usual care	1.1 (0.57)	1.46 (0.47)	0.37 0.20, 0.53	<0.001
2 min walk test (m)	Intervention	99.61 (81.01)	133.33 (47.67)	33.72 9.11, 58.33	0.010
	Usual care	113.50 (60.99)	152.59 (48.69)	39.07 21.05, 57.09	<0.001

Outcome	Group	Baseline Median [IQR]	12-week retest Median [IQR])	Median difference	Wilcoxon signed rank test *Z,p*
SwePASS-NV	Intervention	32 [8.50]	34 [6]	2	−3.28, 0.001
	Usual care	31 [4.75]	34 [4.5]	3	−3.34, <0.001
EQ5D index	Intervention	0.69 [0.40]	0.71 [0.20]	0.02	−1.33, 0.18
	Usual Care	0.72 [0.758]	0.82 [0.18]	0.10	−3.55, <0.001

Discussion

Results show that there were no significant differences between groups following 12 weeks of intensive physiotherapy training with either I-CoreDIST or usual care when adjusted for baseline differences, suggesting that there were no added benefits from the implementation of I-CoreDIST during the sub-acute stage after a stroke. Our results are in line with previous research in stroke rehabilitation where results of clinical trials often are neutral (53, 54), meaning there is no statistical significant difference between groups at endpoint (55). We did encounter some well-known challenges in stroke

TABLE 5 Force platform data. Within- and between-group changes.

Outcome	Group	Baseline	12-week retest	Wilcoxon signed rank test	Mann-Whitney *U* test	
Force platform COP displacements (cm)		**median [IQR]**	**median [IQR]**	***Z*, *p***	***U***	***p***
RMS COPx eyes open	Intervention	1.32 [1.77]	1.28 [1.25]	0.05	280	0.37
	Usual care	1.25 [1.13]	1.39 [1.51]	0.72		
RMS COPy eyes open	Intervention	3.51 [3.16]	2.24 [2.25]	0.01	282	0.26
	Usual care	2.61 [2.83]	2.98 [2.46]	0.38		
RMS COPx eyes closed	Intervention	1.27 [1.34]	1.01 [1.09]	0.32	282	0.51
	Usual care	1.13 [1.33]	1.51 [1.20]	0.57		
RMS COPy eyes closed	Intervention	2.73 [1.72]	2.42 [2.05]	0.03	271	0.68
	Usual care	2.51 [1.44]	2.25 [2.33]	0.84		

rehabilitation RCT's, such as issues with recruitment rates, group heterogeneity and implementation fidelity that that are likely to have impacted upon results (53). In addition, the I-CoreDIST intervention is complex, defined as "containing several interacting components, targeting more than one organizational level of health care and offering considerable flexibility/tailoring" (56, 57). The intervention is low-cost and designed for implementation in clinical practice. While its flexibility allows for broad use and individualization, it is in opposition to the often highly standardized delivery of interventions in an RCT and would require increased power to yield statistically significant results. The registrations of content in treatment also suggest a degree of similarities between interventions as in the returned forms 71.4% of the usual care group reported having included postural control (**Supplementary Material**). However, interviews with a subgroup of participants ($n = 19$) revealed that experiences with participation in the study differed predominantly with regards to the content of therapy (58). Interviews confirm a greater focus on postural and movement control in the intervention group while participants in the usual care group describe an approach of structured training of strength and endurance measured through increased resistance or number of repetition (58).

TABLE 6 SSQOL index scores.

Domain	Intervention group index score ($n = 18$)	Usual Care group index score ($n = 23$)	Mann-Whitney *U* test	
	Median [IQR]	**Median [IQR]**	***U***	***p***
Self-Care	4.90 [0.55]	5.00 [0.20]	256.00	0.15
Vision	5.00 [1.00]	5.00 [0.33]	210.50	0.91
Language	4.80 [0.60]	5.00 [0.20]	306.00	0.005
Mobility	4.58 [0.58]	4.83 [0.67]	285.50	0.04
Work/ productivity	4.67 [1.00]	5.00 [1.00]	226.00	0.59
Upper extremity function	4.60 [1.25]	4.80 [0.20]	300.50	0.01
Thinking	3.33 [2.50]	4.33 [1.67]	266.50	0.11
Personality	4.00 [2.17]	5.00 [0.33]	292.50	0.02
Mood	3.70 [1.85]	4.80 [0.80]	308.50	0.006
Family roles	4.67 [2.08]	5.00 [1.00]	253.00	0.20
Social roles	3.33 [2.14]	4.40 [1.80]	263.00	0.14
Energy	3.33 [2.67]	4.00 [2.33]	243.00	0.34
Total score	4.09 [1.43]	4.56 [0.51]	281.00	0.05

Following 12 weeks of 3–5 weekly physiotherapy sessions, both groups showed both statistically and clinically significant improvements in measures of postural control and balance, sustained low levels of physical activity, and variable improvements in gait speed and distance.

For the primary outcomes, participants in both groups had a mean change near the previously reported MDC for TIS-modNV (29), indicating a true measure of improved trunk control exceeding that is associated with error. Only the usual

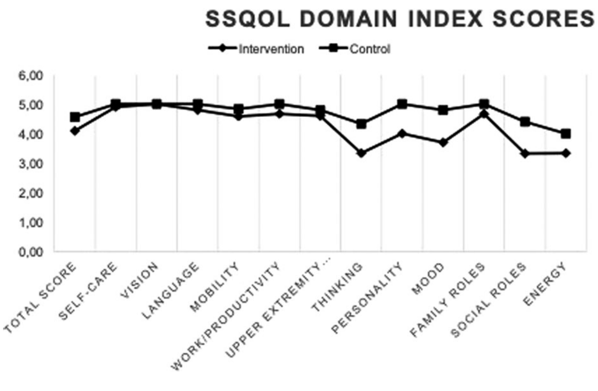


FIGURE 5
SSQOL-scores.

care group showed statistically significant changes in activity levels for the categories of moderate activity and steps, equaling 56 moderate active mins/week and a daily average of 3,327 steps. Despite improvements in balance and that all participants had regained ambulation at 12-week retest, activity levels in both groups are well under the 150–300 min of moderate activity recommended for the general population in Norway (59) and the 20–60 min of aerobic activity 2–3 times/week recommended for the stroke population (60). There was a non-significant reduction in sedative minutes/day (Intervention: −27, Usual care: −7) and an increase in minutes of light activity/day (Intervention: 36, Usual care: 7) in favor of the intervention group. The high levels of sedative time, complete lack of vigorous physical activity and low average number of steps across groups is a cause for concern, both with regards to recovery and secondary prevention (60). Our results are in line with previous research on the stroke population (4), and may suggest suboptimal intensity in or duration of physical therapy sessions at baseline and little uptake of physical activity after the 12-week treatment period and retest. Apart from physical barriers, social factors, support and cognitive impairments have been suggested to influence levels of physical activity after a stroke (61, 62). These issues need further investigation.

With regards to secondary outcomes, improvements in PASS were statistically significant in both groups, though only the usual care group reached the MDC of 2.2 points. Both groups were within the category "good postural control" (31–36 points) at baseline and the previously reported ceiling effect in this measure (34, 63, 64). Both groups exceeded the required change of 5 points constituting substantial clinically important changes on the MiniBESTest (36), that together with improvements in TIS-modNV and PASS suggest overall improved postural control and balance in both groups. Force plate assessments of standing balance with eyes open and eyes closed showed statistically significant reduction in sway amplitudes in both AP and ML directions for the intervention group only implying improved balance control (49). This indicates that the focus on core activation and trunk control as recommended in the literature (13, 15, 16) and implemented in the I-CoreDIST intervention has resulted in reduced postural sway, that generally indicates improved postural stability (49, 65).

In measures of gait speed and distance, both groups exceeded the MCID on 10 MWT preferred pace (41) and fast pace (42), and displayed gait speeds well beyond the <0.8 m/s required for efficient community ambulation (66) at 12-week retest. Only the usual care group reached statistically significant within-group changes in 10 MWT fast pace. This suggests that the I-CoreDIST intervention did not target high walking speeds sufficiently.

Improvements in EQ5D were significant for the usual care group only and SSQOL-scores were generally lower in the intervention group. Group differences in SSQOL were more pronounced in the domains of thinking, personality, mood, social roles and energy than in the domains of self-care, vision, language, mobility, work/productivity and upper extremity function. The SSQOL and EQ5D indicate a lower HRQOL in the intervention group that seems more related to cognitive/mental than physical components. This may suggest a larger proportion of cognitive/mental problems in this group, which may have been caused by the stroke, result from the lower premorbid function, a higher age and stroke severity, or a combination of these. Exercise interventions are known to have small to moderate beneficial effects on HRQOL in physical and mental health domains that diminish at longer-term follow up, and no significant effects on societal or participatory domains, (67). The limited uptake of physical activity after the intervention, as indicated by the activity monitoring at 12-weeks along with lower HRQOL-scores on cognitive/mental components, supports these notions.

Limitations

The major limitation of this study is that it is underpowered ($n = 60$) with regards to the sample size calculations ($n = 74$). In addition, ten participants were lost to follow-up in the intervention group. Four were excluded, and six discontinued physiotherapy or did not attend retest. The reasons given were mainly related to travel time to the physiotherapist/hospital and fear of Covid-19 on public transportation/in the physiotherapy clinic/hospital. With regards to implementation fidelity, further investigations into issues of recruitment and retention, such as barriers and effects of participation for both participants and physiotherapists and the quality of I-CoreDIST training and materials would have been beneficial. Participants in the usual care group, on average received physiotherapy for 2.4 weeks more than those in the intervention group. Registration forms revealed a vulnerability regarding absence, sick leave etc., particularly for the physiotherapists treating the intervention group. Only 1–2 physiotherapists had I-CoreDIST training on most sites, resulting in limited ability for another therapist to cover in case of absence. No additional training was required to treat the usual care group. These issues were further reinforced by Covid regulations and reallocation of staff related to the handling of pandemic. The 12-week follow up period is relatively short and a long-term follow up would have been beneficial.

Conclusion

A 12-week physiotherapy program with either I-CoreDIST or usual care implemented during the first 12 weeks showed no differences between groups, except for significant gains in HRQOL in favor of the usual care group. Both groups showed significant improvements on measures of postural control, balance and gait.

Data availability statement

The datasets presented in this article are not readily available as we do not have permission from the ethical committee to share data. Requests to access the datasets should be directed to marianne.sivertsen2@nordlandssykehuset.no.

Ethics statement

The study involved human participants and was reviewed and approved by the Regional Committee for Medical Research Ethics North Norway (REK North: 2017/1961). All patients/participants provided written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

BN and ECA is responsible for the idea and development of the CoreDIST-intervention, and the adaptation to stroke patients together with MS. All authors have contributed to the design of the project and formulation of research goals and aims. BN and MS have been responsible for project administration and MS has been the site principal investigator. MS has been responsible for the investigation and data curation. All authors have participated in creating a statistical analysis plan. MS conducted the formal analysis of data, supervised by BN, KBA and ECA. MS drafted the manuscript. All authors contributed to the article and approved the submitted version.

Funding

The study was funded by the Northern Norway Regional Health Authority (Grant Number: HNF1459-19).

Acknowledgments

We would like to thank the individuals who participated in this study, Nordland and Nord-Trøndelag Hospital Trust for their support, the four physical therapists that conducted the testing and the physical therapists who treated the patients, the participating municipalities and the user representative. We extend our gratitude to Tonje Braathen for help with statistical analysis.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2022.987601/full#supplementary-material.

References

1. Haley WE, Roth DL, Kissela B, Perkins M, Howard G. Quality of life after stroke: a prospective longitudinal study. *Qual Life Res.* (2011) 20(6):799–806. doi: 10.1007/s11136-010-9810-6

2. Sjoholm A, Skarin M, Churilov L, Nilsson M, Bernhardt J, Linden T. Sedentary behaviour and physical activity of people with stroke in rehabilitation hospitals. *Stroke Res Treat.* (2014) 2014:591897. doi: 10.1155/2014/591897

3. Barrett M, Snow JC, Kirkland MC, Kelly LP, Gehue M, Downer MB, et al. Excessive sedentary time during in-patient stroke rehabilitation. *Top Stroke Rehabil.* (2018) 25(5):366–74. doi: 10.1080/10749357.2018.1458461

4. Fini NA, Holland AE, Keating J, Simek J, Bernhardt J. How physically active are people following stroke? Systematic review and quantitative synthesis. *Phys Ther.* (2017) 97(7):707–17. doi: 10.1093/ptj/pzx038

5. Saunders DH, Mead GE, Fitzsimons C, Kelly P, van Wijck F, Verschuren O, et al. Interventions for reducing sedentary behaviour in people with stroke. *Cochrane Database Syst Rev.* (2021) (6). doi: 10.1002/14651858.CD012996.pub2

6. Pollock A, Baer G, Campbell P, Choo PL, Forster A, Morris J, et al. Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev.* (2014) (4). doi: 10.1002/14651858.CD001920.pub3

7. Verbeek JM, van Wegen E, van Peppen R, van der Wees PJ, Heniks E, Rietberg M, et al. What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. *PloS One.* (2014) 9(2):e87987. doi: 10.1371/journal.pone.0087987

8. Dee M, Lennon O, O'Sullivan C. A systematic review of physical rehabilitation interventions for stroke in low and lower-middle income

countries. *Disabil Rehabil*. (2020) 42(4):473–501. doi: 10.1080/09638288.2018.1501617

9. DiCarlo JA, Gheihman G, Lin DJ. Reimagining stroke rehabilitation and recovery across the care continuum: results from a design-thinking workshop to identify challenges and propose solutions. *Arch Phys Med Rehabil*. (2021) 102 (8):1645–57. doi: 10.1016/j.apmr.2021.01.074

10. Langhorne P, Bernhardt J, Kwakkel G. Stroke care 2: stroke rehabilitation. *Lancet*. (2011) 377(9778):1693–702. doi: 10.1016/S0140-6736(11)60325-5

11. Likhi M, Jidesh VV, Kanagaraj R, George JK. Does trunk, arm, or leg control correlate best with overall function in stroke subjects? *Top Stroke Rehabil*. (2013) 20(1):62–7. doi: 10.1310/tsr2001-62

12. Verheyden G, Vereeck L, Truijen S, Troch M, Herregodts I, Lafosse C, et al. Trunk performance after stroke and the relationship with balance, gait and functional ability. *Clin Rehabil*. (2006) 20(5):451–8. doi: 10.1191/0269215505cr955oa

13. Van Criekinge T, Truijen S, Schröder J, Maebe Z, Blanckaert K, van der Waal C, et al. The effectiveness of trunk training on trunk control, sitting and standing balance and mobility post-stroke: a systematic review and meta-analysis. *Clin Rehabil*. (2019) 33(6):992–1002. doi: 10.1177/0269215519830159

14. Isho T, Usuda S. Association of trunk control with mobility performance and accelerometry-based gait characteristics in hemiparetic patients with subacute stroke. *Gait Posture*. (2015) 44:89–93. doi: 10.1016/j.gaitpost.2015.11.011

15. Cabrera-Martos I, Ortiz-Rubio A, Torres-Sánchez I, López-López L, Jarrar M, Valenza MC. The effectiveness of core exercising for postural control in patients with stroke: a systematic review and meta-analysis. *PM&R*. (2020) 12 (11):1157–68. doi: 10.1002/pmrj.12330

16. Gamble K, Chiu A, Peiris C. Core stability exercises in addition to usual care physiotherapy improve stability and balance after stroke: a systematic review and meta-analysis. *Arch Phys Med Rehabil*. (2021) 102(4):762–75. doi: 10.1016/j.apmr.2020.09.388

17. Borges Souza DC, Santos M, da Silva Ribeiro NM, Maldonado IL. Inpatient trunk exercises after recent stroke: an update meta-analysis of randomized controlled trials. *J Alzheimers Dis*. (2019) 44(3):369–77. doi: 10.3233/NRE-182585

18. Ravichandran H, Sharma HR, Haile TG, Gelaw AY, Gebremeskel BF, Janakiraman B. Effects of trunk exercise with physioball to improve trunk balance among subjects with stroke: a systematic review and meta-analysis. *J Exerc Rehabil*. (2020) 16(4):313–24. doi: 10.12965/jer.2040292.146

19. Krishnan V, Kanekar N, Aruin AS. Anticipatory postural adjustments in individuals with multiple sclerosis. *Neurosci Lett*. (2012) 506(2):256–60. doi: 10.1016/j.neulet.2011.11.018

20. Curuk E, Lee Y, Aruin AS. Individuals with stroke use asymmetrical anticipatory postural adjustments when counteracting external perturbations. *Motor Control*. (2019) 23(4):461–71. doi: 10.1123/mc.2018-0083

21. Levin MF, Demers M. Motor learning in neurological rehabilitation. *Disabil Rehabil*. (2020):1–9.

22. Frykberg GE, Vasa R. Neuroplasticity in action post-stroke: challenges for physiotherapists. *Eur J Physiother*. (2015) 17:56–65. doi: 10.3109/21679169.2015.1039575

23. Kibler WB, Press J, Sciascia A. The role of core stability in athletic function. *Sports Med*. (2006) 36(3):189–98. doi: 10.2165/00007256-200636030-00001

24. Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, et al. Action plan for stroke in Europe 2018–2030. *Eur Stroke J*. (2018) 3 (4):309–36. doi: 10.1177/2396987318808719

25. Winstein CJ, Stein J, Arena R, Bates B, Cherney LR, Cramer SC, et al. Guidelines for adult stroke rehabilitation and recovery: a guideline for healthcare professionals from the American heart association/American stroke association. *Stroke*. (2016) 47(6):e98–169. doi: 10.1161/STR.0000000000000098

26. Normann B, Arntzen EC, Sivertsen M. Comprehensive core stability intervention and coordination of care in acute and subacute stroke rehabilitation-a pilot study. *Eur J Physiother*. (2019) 21(4):187–96. doi: 10.1080/21679169.2018.1508497

27. Norwegian Directorate of Health. *Nasjonal faglig retningslinje for behandling og rehabilitering ved hjerneslag. (National guidelines for treatment and rehabilitation in stroke)*. Oslo: Norwegian Directorate of Health (2017).

28. Gjelsvik B, Breivik K, Verheyden G, Smedal T, Hofstad H, Strand LI. The trunk impairment scale - modified to ordinal scales in the Norwegian version. *Disabil Rehabil*. (2012) 34(16):1385–95. doi: 10.3109/09638288.2011.645113

29. Aadland E, Ylvisaker E. Reliability of the actigraph GT3X + accelerometer in adults under free-living conditions. *PLoS One*. (2015) 10(8):e0134606. doi: 10.1371/journal.pone.0134606

30. Campos C, DePaul VG, Knorr S, Wong JS, Mansfield A, Patterson KK. Validity of the ActiGraph activity monitor for individuals who walk slowly post-stroke. *Top Stroke Rehabil*. (2018) 25(4):295–304. doi: 10.1080/10749357.2018.1446487

31. Gebruers N, Vanroy C, Truijen S, Engelborghs S, De Deyn PP. Monitoring of physical activity after stroke: a systematic review of accelerometry-based measures. *Arch Phys Med Rehabil*. (2010) 91(2):288–97. doi: 10.1016/j.apmr.2009.10.025

32. Benaim C, Perennou DA, Villy J, Rousseaux M, Pelissier JY. Validation of a standardized assessment of postural control in stroke patients - the postural assessment scale for stroke patients (PASS). *Stroke*. (1999) 30(9):1862–8. doi: 10.1161/01.STR.30.9.1862

33. Breistein K, Gjelsvik BEB, Jørgensen L. The postural assessment scale for stroke patients: translation into Norwegian, cultural adaptation, and examination of reliability. *Eur J Physiother*. (2017) 19(4):207–14. doi: 10.1080/21679169.2017.1334817

34. Chien C-WBS, Hu M-HP, Tang P-FP, Sheu C-FP, Hsieh C-LP. A comparison of psychometric properties of the smart balance master system and the postural assessment scale for stroke in people who have had mild stroke. *Arch Phys Med Rehabil*. (2007) 88(3):374–80. doi: 10.1016/j.apmr.2006.11.019

35. Hamre C, Botolfsen P, Tangen GG, Helbostad JL. Interrater and test-retest reliability and validity of the Norwegian version of the BESTest and mini-BESTest in people with increased risk of falling. *BMC Geriatr*. (2017) 17(1):92. doi: 10.1186/s12877-017-0480-x

36. Beauchamp MK, Niebuhr R, Roche P, Kirkwood R, Sibley KM. A prospective study to establish the minimal clinically important difference of the Mini-BESTest in individuals with stroke. *Clin Rehabil*. (2021) 35(8):1207–15. doi: 10.1177/02692155211025131

37. Stergiou N. *Innovative analyses of human movement*. Champaign, IL: Human Kinetics (2004).

38. Gray VL, Ivanova TD, Garland SJ. Reliability of center of pressure measures within and between sessions in individuals post-stroke and healthy controls. *Gait Posture*. (2014) 40(1):198–203. doi: 10.1016/j.gaitpost.2014.03.191

39. Busk H, Holm P, Skou S, Seitner S, Siemsen T, Wienecke T. Inter-rater reliability and agreement of 6 minute walk test and 10 meter walk test at comfortable walk speed in patients with acute stroke. *Physiother Theory Pract*. (2022):1–9. doi: 10.1080/09593985.2022.2030830. [Epub Ahead of Print]

40. Cheng DK-Y, Dagenais M, Alsbury-Nealy K, Legasto JM, Scodras S, Aravind G, et al. Distance-limited walk tests post-stroke: a systematic review of measurement properties. *NeuroRehabilitation*. (2021) 48(4):413–39. doi: 10.3233/NRE-210026

41. Tilson JK, Sullivan KJ, Cen SY, Rose DK, Koradia CH, Azen SP, et al. Meaningful gait speed improvement during the first 60 days poststroke: minimal clinically important difference. *Phys Ther*. (2010) 90(2):196–208. doi: 10.2522/ptj.20090079

42. Hiengkaew VP, Jitaree KM, Chaiyawat PP. Minimal detectable changes of the berg balance scale, fugl-Meyer assessment scale, timed “up & go” test, gait speeds, and 2-Minute walk test in individuals with chronic stroke with different degrees of ankle plantarflexor tone. *Arch Phys Med Rehabil*. (2012) 93 (7):1201–8. doi: 10.1016/j.apmr.2012.01.014

43. Kosak M, Smith T. Comparison of the 2-, 6-, and 12-minute walk tests in patients with stroke. *J Rehabil Res Dev*. (2005) 42(1):103–7. doi: 10.1682/JRRD.2003.11.0171

44. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol group. *Ann Med*. (2001) 33(5):337–43. doi: 10.3109/07853890109002087

45. Cameron LJ, Wales K, Casey A, Pike S, Jolliffe L, Schneider EJ, et al. Self-reported quality of life following stroke: a systematic review of instruments with a focus on their psychometric properties. *Qual Life Res*. (2022) 31(2):329–42. doi: 10.1007/s11136-021-02944-9

46. Hunger M, Sabariego C, Stollenwerk B, Cieza A, Leidl R. Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing rehabilitation. *Qual Life Res*. (2012) 21(7):1205–16. doi: 10.1007/s11136-011-0024-3

47. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. *Stroke*. (1999) 30(7):1362–9. doi: 10.1161/01.STR.30.7.1362

48. Pedersen SG, Heiberg GA, Nielsen JF, Friborg O, Stabel HH, Anke A, et al. Validity, reliability and Norwegian adaptation of the stroke-specific quality of life (SS-QOL) scale. *SAGE Open Med*. (2018) 6:2050312117752031. -. doi: 10.1177/2050312117752031

49. Mansfield A, Inness EL. Force plate assessment of quiet standing balance control: perspectives on clinical application within stroke rehabilitation. *Rehabil Process Outcome*. (2015) 2015. doi: 10.4137/RPO.S20363

50. Szende A, Oppe M, Devlin N, EuroQol G. *EQ-5D Value sets: inventory, comparative review and user guide*. Dordrecht: Springer Netherlands: Imprint: Springer (2007).

51. Wittrup-Jensen KU, Lauridsen J, Gudex C, Pedersen KM. Generation of a danish TTO value set for EQ-5D health states. *Scand J Public Health*. (2009) 37 (5):459–66. doi: 10.1177/1403494809105287

52. Waehler IS, Saltvedt I, Lydersen S, Fure B, Askim T, Einstad MS, et al. Association between in-hospital frailty and health-related quality of life after stroke: the nor-COAST study. *BMC Neurol*. (2021) 21(1):100. doi: 10.1186/s12883-021-02128-5

53. Stinear CM, Lang CE, Zeiler S, Byblow WD. Advances and challenges in stroke rehabilitation. *Lancet Neurol*. (2020) 19(4):348–60. doi: 10.1016/S1474-4422(19)30415-6

54. Langhorne P, Coupar F, Pollock A. Motor recovery after stroke: a systematic review. *Lancet Neurol*. (2009) 8(8):741–54. doi: 10.1016/S1474-4422(09)70150-4

55. Bresee L. The importance of negative and neutral studies for advancing clinical practice. *Can J Hosp Pharm*. (2017) 70(6):403–4. doi: 10.4212/cjhp.v70i6.1706

56. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new medical research council guidance. *Br Med J (Clin Res Ed)*. (2008) 337:a1655. doi: 10.1136/bmj.a1655

57. Richards DA, Hallberg IR. *Complex interventions in health: An overview of research methods*. Beaverton: Ringgold Inc. (2015).

58. Sivertsen M, De Jaegher H, Arntzen EC, Alstadhaug KB, Normann B. Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke: a qualitative study. *Physiother Res Int*. (2022) 27 (3):e1948. doi: 10.1002/pri.1948

59. The Norwegian Directorate of Health. In: Health TNDo, editors. *Physical activity in prevention and treatment*. Oslo: The Norwegian Directorate of Health (2022). Avaiable at: https://www.helsedirektoratet.no/faglige-rad/fysisk-aktivitet-i-forebygging-og-behandling

60. Billinger SA, Arena R, Bernhardt J, Eng JJ, Franklin BA, Johnson CM, et al. Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American heart association/American stroke association. *Stroke*. (2014) 45(8):2532–53. doi: 10.1161/STR.0000000000000022

61. Viktorisson A, Andersson EM, Lundstroem E, Sunnerhagen KS. Levels of physical activity before and after stroke in relation to early cognitive function. *Sci Rep*. (2021) 11(1):9078. doi: 10.1038/s41598-021-88606-9

62. Espernberger KR, Fini NA, Peiris CL. Personal and social factors that influence physical activity levels in community-dwelling stroke survivors: a systematic review of qualitative literature. *Clin Rehabil*. (2021) 35(7):1044–55. doi: 10.1177/0269215521993690

63. Huang Y-J, Lin G-H, Lee S-C, Hsieh C-L. A comparison of the responsiveness of the postural assessment scale for stroke and the berg balance scale in patients with severe balance deficits after stroke. *J Geriatr Phys Ther*. (2020) 43(4):194–8. doi: 10.1519/JPT.0000000000000247

64. Persson CU, Kjellberg S, Lernfelt B, Westerlind E, Cruce M, Hansson P-O. Risk of falling in a stroke unit after acute stroke: the fall study of gothenburg (FallsGOT). *Clin Rehabil*. (2018) 32(3):398–409. doi: 10.1177/0269215517728325

65. Quijoux F, Nicolaï A, Chairi I, Bargiotas I, Ricard D, Yelnik A, et al. A review of center of pressure (COP) variables to quantify standing balance in elderly people: algorithms and open-access code. *Physiol Rep*. (2021) 9(22):e15067. doi: 10.14814/phy2.15067

66. Bowden MG, Balasubramanian CK, Behrman AL, Kautz SA. Validation of a speed-based classification system using quantitative measures of walking performance poststroke. *Neurorehabil Neural Repair*. (2008) 22(6):672–5. doi: 10.1177/1545968308318837

67. Ali A, Tabassum D, Baig SS, Moyle B, Redgrave J, Nichols S, et al. Effect of exercise interventions on health-related quality of life after stroke and transient ischemic attack A systematic review and meta-analysis. *Stroke*. (2021) 52 (7):2445–55. doi: 10.1161/STROKEAHA.120.032979

Supplementary material:

1. Contents of physiotherapy in the usual care group

Content of physiotherapy sessions	Number of participants where activity was part of physiotherapy, n (%) N=14	Activity was part of physiotherapy treatment for number of weeks during 12-week follow-up, median [IQR]
Balance training	13.0 (92.9)	9.0 [6.0]
Strength training	13.0 (92.9)	9.0 [7.0]
Gait	10.0 (71.4)	8.5 [12.0]
Passive movements	2.0 (14.3)	0.0 [0.0]
Soft tissue mobilisations	5.0 (35.7)	0.0 [2.0]
Active assisted movements	7.0 (50.0)	0.5 [2.0]
Endurance training	14.0 (100.0)	9.0 [5.0]
Functional training	9.0 (64.3.)	2.5 [12.0]
Stretching	4.0 (28.6)	0.0 [2.0]
Heat	1.0 (7.1)	0.0 [0.0]
Postural control	10.0 (71.4)	4.0 [12.0]
Independent exercises in gym	12.0 (85.7)	8.0 [8.0]
Specific somatosensory stimulation	9.0 (64.3)	2.5 [6.0]
Pilates	0.0 (0.0)	0.0 [0.0]
Yoga	1.0 (7.1)	0.0 [0.0]
Sling-exercises	0.0 (0.0)	0.0 [0.0]
Outdoor activities	9.0 (64.3)	2.0 [8.0]

2. Content of physioterapy, I-CoreDIST group

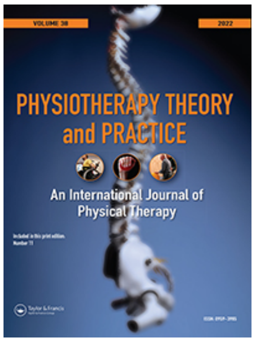
Exercises	Number of participants where activity/Exercise was part of physiotherapy n (%). N=16	Activity was part of physiotherapy treatment for number of weeks during 12-week follow-up, median [IQR]
A: Sensori- and oculomotor function		
Sensorimotor activation and mobility of the foot and ankle	15.0 (93.8)	5.5 [7.0]
Sensorimotor activation and mobility of the hands	12.0 (75.0)	1.0 [4.0]
Sensorimotor activation of the face	0.0 (0.0)	0.0 [0.0]
Oculomotor exercises	6.0 (37.5)	0.0 [2.0]
B: Supine		
Bent banana-straight banana	8.0 (50.0)	0.5 [3.0]
The yes	2.0 (12.5)	0.0 [0.0]
The spider	6.0 (37.5)	0.0 [4.0]
The bridge	11.0 (68.8)	3.0 [5.0]
The shrimp	10.0 (62.5)	2.5 [6.0]
Standing on the wall	10.0 (62.5)	2.0 [4.0]
Balancing on the wall	6.0 (37.5)	0.0 [3.0]
Walking on the wall	10.0 (62.5)	2.5 [7.0]
The crab-wiggle/ball play	2.0 (12.5)	0.0 [0.0]
Walking on air	4.0 (25.0)	0.0 [1.0]
Sit up	8.0 (50.0)	1.0 [4.0]
Sit up 2	4.0 (25.0)	0.0 [2.0]

C: Side-lying		
The stick	3.0 (18.8)	0.0 [0.0]
Reach for the stars	2.0 (12.5)	0.0 [0.0]
D: Prone		
The eagle	3.0 (18.8)	0.0 [0.0]
The cat	6.0 (37.5)	0.0 [4.0]
E: Sitting		
Slowly diving	5.0 (31.3)	0.0 [2.0]
Reach all over	10.0 (62.5)	2.0 [4.0]
Rolling the ball	12.0 (75.0)	1.5 [4.0]
Hands up	6.0 (37.5)	0.0 [1.0]
The butterfly	3.0 (18.8)	0.0 [0.0]
Nodding	1.0 (6.3)	0.0 [0.0]
The angel	4.0 (25.0)	0.0 [1.0]
Pluto	1.0 (6.3)	0.0 [1.0]
Pelvic walk	8.0 (50.0)	0.5 [2.0]
Stand up	7.0 (43.8)	0.0 [3.0]
All rise	8.0 (50.0)	1.0 [2.0]
High sit to stand	5.0 (31.3)	0.0 [3.0]
F: Standing		
High kneeling	4.0 (25.0)	0.0 [0.0]
Squats	15.0 (93.8)	5.5 [6.0]
The wiggle no 1	7.0 (43.8)	0.0 [4.0]
The wiggle no 2	9.0 (56.3)	1.5 [6.0]
Calf-rise	10.0 (62.5)	1.5 [4.0]
The corner	6.0 (37.5)	0.0 [2.0]

The march	14.0 (87.5)	5.0 [5.0]
Play ball	7.0 (43.8)	0.0 [2.0]
The waiter	5.0 (31.3)	0.0 [1.0]
The bounce	7.0 (43.8)	0.5 [3.0]
G: Stepping and walking		
Stepping	8.0 (50)	0.5 [4.0]
Walking the ball	3.0 (18.8)	0.0 [0.0]
Push the therapist	6.0 (37.5)	0.0 [1.0]
Guided walking	10.0 (62.5)	1.5 [7.0]
Run away	4.0 (25.0)	0.0 [1.0]
Stairway to heaven	11.0 (68.8)	3.0 [5.0]

Paper II

Sivertsen, M., De Jaegher, H., Alstadhaug, K. B., Arntzen, E. C., & Normann, B. (2022). The precarity of patient participation - a qualitative interview study of experiences from the acute stroke and rehabilitation journey. *Physiotherapy theory and practice*, 1–16. Advance online publication. https://doi.org/10.1080/09593985.2022.2140319



Taylor & Francis
Taylor & Francis Group

Physiotherapy Theory and Practice
An International Journal of Physical Therapy

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/iptp20

The precarity of patient participation - a qualitative interview study of experiences from the acute stroke and rehabilitation journey

Marianne Sivertsen, Hanne De Jaegher, Karl Bjørnar Alstadhaug, Ellen Christin Arntzen & Britt Normann

To cite this article: Marianne Sivertsen, Hanne De Jaegher, Karl Bjørnar Alstadhaug, Ellen Christin Arntzen & Britt Normann (2022): The precarity of patient participation - a qualitative interview study of experiences from the acute stroke and rehabilitation journey, Physiotherapy Theory and Practice, DOI: 10.1080/09593985.2022.2140319

To link to this article: https://doi.org/10.1080/09593985.2022.2140319

PHYSIOTHERAPY THEORY AND PRACTICE
https://doi.org/10.1080/09593985.2022.2140319

Taylor & Francis
Taylor & Francis Group

REPORT

The precarity of patient participation - a qualitative interview study of experiences from the acute stroke and rehabilitation journey

Marianne Sivertsen MSc PT[a,b], Hanne De Jaegher PhD[c,d], Karl Bjørnar Alstadhaug MD, PhD[e,f], Ellen Christin Arntzen PhD PT[b,g], and Britt Normann PhD, PT[b,g]

[a]Department of Health and Care Sciences, UiT the Arctic University of Norway, Tromsoe, Norway; [b]Department of Physiotherapy, Nordland Hospital Trust, Bodoe, Norway; [c]Department of Philosophy, University of the Basque Country, Avenida de Tolosa, San Sebastián, Spain; [d]University of Sussex School of Psychology, Brighton, UK; [e]Department of Clinical Medicine, UiT the Arctic University of Norway, Langnes, Tromsoe, Norway; [f]Department of Neurology, Nordland Hospital Trust, Bodoe, Norway; [g]Faculty of Nursing and Health Sciences, Nord University, Bodoe, Norway

ABSTRACT

Introduction: Active patient participation is an important factor in optimizing post-stroke recovery, yet it is often low, regardless of stroke severity. The reasons behind this trend are unclear.
Purpose: To explore how people who have suffered a stroke, perceive the transition from independence to dependence and whether their role in post-stroke rehabilitation influences active participation.
Methods: In-depth interviews with 17 people who have had a stroke. Data were analyzed using systematic text condensation informed by the concept of autonomy from enactive theory.
Results: Two categories emerged. The first captures how the stroke and the resultant hospital admission produces a shift from being an autonomous subject to "an object on an assembly line." Protocol-based investigations, inactivity, and a lack of patient involvement predominantly determine the hospital context. The second category illuminates how people who have survived a stroke passively adapt to the hospital system, a behavior that stands in contrast to the participatory enablement facilitated by community. Patients feel more prepared for the transition home after in-patient rehabilitation rather than following direct discharge from hospital.
Conclusion: Bodily changes, the traditional patient role, and the hospital context collectively exacerbate a reduction of individual autonomy. Thus, an interactive partnership between people who survived a stroke and multidisciplinary professionals may strengthen autonomy and promote participation after a stroke.

ARTICLE HISTORY
Received 28 April 2021
Revised 8 October 2022
Accepted 8 October 2022

KEYWORDS
Stroke; rehabilitation; participation; enactive theory; physiotherapy; autonomy; action; relationship

Introduction

Acute stroke care has improved considerably over the past several decades, as practices and systems for rapid and efficient assessment, diagnosis, and treatment have been refined (Phipps and Cronin, 2020). For reducing mortality rates and loss of function, the practice of treating patients in a dedicated stroke unit has been the single most important factor (Langhorne and Ramachandra, 2020) but this development has also been driven by the more expeditious recognition of stroke symptoms along with the combination of acute medical treatment and early multidisciplinary rehabilitation including physiotherapy (Bernhardt, Godecke, Johnson, and Langhorne, 2017; Langhorne and Ramachandra, 2020). After a stroke, active patient participation involving engagement in meaningful activities is essential for bolstering the neuroplastic basis for functional recovery (Brodal, 2010). Indeed, since neuroplasticity is most prominent in the initial phase after a neural lesion (Bernhardt, Godecke, Johnson, and Langhorne, 2017) patient participation is especially exigent in the stroke unit and the subacute rehabilitation facility if patients are to recover the abilities used for daily living.

Yet, despite the manifest importance of patient participation, current practices can often hinder or even discourage it during both acute admission and subsequent rehabilitation; patients remain inactive (Field et al., 2013) and systemically excluded from decision-making (Légaré et al., 2018). While research has demonstrated that patient participation can optimize recovery (Elloker and Rhoda, 2018; Ezekiel et al., 2019; Jones et al., 2021; Paolucci et al., 2012), in reality patient participation in social, leisure, or professional activities after a stroke are consistently reported to be low irrespective of initial stroke severity, level of disability, or geographical location (Eriksson, Baum, Wolf, and

CONTACT Marianne Sivertsen marianne.sivertsen2@nordlandssykehuset.no Department of Health and Care Sciences, UiT the Arctic University of Norway, P.O. Box 6050 Langnes, Tromsoe N-9037, Norway

Connor, 2013; Foley, Nicholas, Baum, and Connor, 2019; Paolucci et al., 2012). Foley, Nicholas, Baum, and Connor (2019) suggested that factors other than the presence of impairments are crucial to consider when investigating active participation after a stroke. There is a need for more in-depth contextualization and exploration of the reasons behind restricted participation and how this proclivity develops from the acute incident and across the rehabilitation journey. After all, the experience and consequences of a stroke are not determined exclusively by the body, but rather are shaped by the whole set of institutions, practices, and networks through which the individual passes often over the course of months or years.

Participation is a complex and subjective term, one difficult to delimit and measure and yet nonetheless important to investigate and facilitate (Eriksson, Baum, Wolf, and Connor, 2013; Ezekiel et al., 2019). Definitions of participation in previous reports span taking part in therapy, training, and activities (Paolucci et al., 2012), contributing to decision-making (Légaré et al., 2018), and involvement in a life situation (World Health Organization, 2013). For the purpose of this paper we apply Mallinson and Hammel's (2010) perspective that *"participation necessarily occurs at the intersection of what a person can do, has the affordances to do, and is not prevented from doing by the world in which he or she lives and seeks to participate."* This conceptualization of participation encompasses both social and everyday activity participation, a scope that would include the rehabilitation process immediately following a stroke.

Autonomy, a requisite of participation, is reportedly reduced over the long term among people who survived a stroke (Palstam, Sjödin, and Sunnerhagen, 2019). Moreover, active interaction, engagement, and a sense of belonging promote participation (Foley, Nicholas, Baum, and Connor, 2019) yet it is not clear what restricts these after a stroke. In a review of qualitative studies on post-stroke physical rehabilitation Luker et al. (2015) called for a deeper consideration of how we engage with people who have survived a stroke, and of how the physical and regulatory environments of hospitals influence recovery more broadly. Only by understanding how patient participation is facilitated and constrained by the regulatory environment of hospitals can we properly support the recovery of those who have had a stroke both during admission and after discharge.

To understand the complexity of post-stroke patient participation, it is instructive to explore how persons who survived a stroke have experienced the stroke and their journey toward recovery. To aid in the interpretation of such first-person experiences we turn to enactive theory, as it can illuminate previously under-investigated aspects of patient participation following a stroke. Within this framework, autonomy captures how individuals generate and maintain their identity in interaction with their various (physical and social) environments (Thompson, 2007). What is interesting about this approach is that just like individuals are autonomous, the social interaction processes that emerge between them can also take on a certain autonomy (De Jaegher and Di Paolo, 2007). Social interactions can develop a temporary 'life of their own,' as they can coordinate the behaviors of their participants. In addition to this "local" autonomy of interactive processes, practices around behaviors are often also highly conventionalized and rooted in strong social norms (De Jaegher, Peräkylä, and Stevanovic, 2016). Institutional settings like hospitals may involve or even demand specific pre-coordinated applications of these rules such as with staff-patient relations. Tensions then arise between the self-organization of the patient as an autonomous living being and the interactional coordination which is partly determined by social norms. The concepts of self-organization and the role of social norms may reveal heretofore unrecognized dimensions of patient participation, which could improve the follow-up practices for people who have had a stroke. The purpose of the present study is to explore how people who have survived a stroke perceive the transition from being an independent individual to a dependent one, their role in post-stroke rehabilitation, and the subsequent influence of these self-perceptions on participation in their life and in society. In exploring these experiences, we addressed the following research question: What are the basic environmental and personal factors that influence patient participation during the acute and subacute phases after a stroke?

Methods

Design

Based on the research question, qualitative interviews within a phenomenological hermeneutic methodological framework was chosen, as it allows knowledge to be derived from lived experiences (Cresswell and Poth, 2018; Malterud, 2015).

Theoretical framework

In the analysis of data, enactive theory was chosen as the framework for interpretation. Enactive theory has previously been utilized quite successfully within the fields of neurorehabilitation and physiotherapy (Hay, Connelly, and Kinsella, 2016; Lahelle, Øberg, and Normann, 2020; Martinez-Pernia, 2020; Normann, 2020). It is rooted in phenomenology and embodied cognition and it has strong links to dynamic systems theory (Varela, Thompson, and Rosch, 2016). Five closely related concepts constitute the enactive approach: 1) autonomy; 2) sense-making; 3) emergence; 4) experience; and 5) embodiment. Most relevant for this study is the term autonomy which is defined as *"a system composed of several processes that actively generate and sustain an identity under precarious conditions"* (De Jaegher and Di Paolo, 2007). In this context, the term precarious points to the fact that isolated components would diminish or extinguish in absence of the organization of the system as a network of processes. Autonomy thus refers to the ability of an organism (i.e. a living cell or a human being) to behave as a coherent, self-determining, and self-sustaining unit as opposed to a machine that is controlled from the outside (Di Paolo, Rohde, and De Jaegher, 2010). As cognitive systems, we are also autonomous in an interactive sense vis-à-vis our engagement with our environment. We actively participate in the generation of meaning through our bodies and actions; we "enact a world." This creation and appreciation of meaning is called sense-making (Di Paolo, Rohde, and De Jaegher, 2010). The concept of emergence describes how a new property or process emerges out of the interaction of different existing processes or events. Experience is intertwined with being alive and immersed in a world of significance, and it is viewed as a skillful aspect of embodied activity. Within the enactive framework, cognition equals embodied action; the individual is understood as an experiencing and expressing body (i.e. an embodied self) in relation with others through the sensorimotor processes of social interaction, where social understanding and sense-making are interactional and inter-corporal processes (Fuchs and De Jaegher, 2009; Varela, Thompson, and Rosch, 2016).

Context of the study

This study was nested within a randomized controlled trial (RCT) (ClinicalTrials.gov Identifier: NCT04069767) comparing a new physiotherapy intervention I-CoreDIST[1] to usual care (Table 1). Informants were recruited from those already included in the RCT. The study was conducted from December 2019 to December 2020 and encompassed two stroke units, their collaborating rehabilitation units, and neighboring municipalities in two regions of Norway. Inclusion and exclusion criteria are outlined in Table 2.

Following admission to a stroke unit in Norway patients are usually discharged to an in-patient rehabilitation unit, to their home, or to residential care depending on their level of independence. About 45% of patients are discharged home after a stroke, the majority without help (Norwegian Stroke Registry, 2019). All participants in the RCT, regardless of group allocation, received physiotherapy; this was either on a daily basis at an in-patient rehabilitation unit or three times per week at the participant's home or an outpatient clinic. In most cases this represents a more intensive physiotherapy follow-up course than usually offered, and in this respect, we have created a somewhat artificial pathway for the purpose of the RCT.

Participants and sample

Following approval from the Regional Committee for Medical and Health Research Ethics in Norway (REK North: 2017/1961), recruitment for the RCT was conducted at the two stroke units by designated physiotherapists. Informed, written consent was obtained for all participants. To ensure a rich material and to strengthen the credibility of the study, informants were

Table 1. I-Core DIST intervention and standard care.

I-CoreDIST	Standard Care
Physiotherapy daily if in-patient or 3 days/week if outpatient.	Physiotherapy daily if in-patient or 3 days/week if outpatient.
12-week follow up	12-week follow up
Structure for assessment	No guidelines regarding physiotherapy approach
Clinical reasoning charts	
Booklet containing 44 illustrated exercises, each with five levels of difficulty	

Table 2. Inclusion and exclusion criteria for the RCT.

Inclusion Criteria	Exclusion criteria
Admitted to the stroke unit with confirmed stroke	Unable to cooperate in physiotherapy
Age: 18–85	Ongoing substance-abuse
Premorbid modified Ranking Scale 0–3	Dementia or other severe disease preventing rehabilitation
Able to sit unsupported for 10 seconds	
Trunk Impairment Scale -Norwegian version score <15	

purposively sampled for interview (Cresswell and Poth, 2018). Seventeen participants (ID1–ID17) were strategically selected from both study arms and from different geographical locations. To further ensure the diversity of the sample these informants also vary in gender, age, stroke location, and level of disability. The characteristics of the informants are shown in Table 3. We initially aimed to interview the informants 6–12 weeks after inclusion, but due to challenges with RCT recruitment mainly due to lockdown and subsequent restrictions related to the Covid-19 pandemic, informants for the interview study were sampled from the initial 40 RCT participants rather than from the full sample which was expected to be 80. This resulted in some being interviewed up to 38 weeks after inclusion.

Data collection

The interviews were conducted and recorded by MS between December 2019 and December 2020. They lasted between 20 and 91 minutes, constituting a total interview time of 774 minutes and an average interview-time of 45.5 minutes. The first six interviews were held face-to-face in a location of the informant's choosing. The remaining interviews were, due to Covid-19 restrictions, performed over the phone, using a loudspeaker and a separate digital recorder. A theme-based interview guide with open-ended questions addressed the informants' experiences and initiated their reflections on: 1) the acute situation; 2) the participation in daily tasks and activities in hospital; 3) the transfer from hospital to home or to rehabilitation unit; 4) the daily activities at home; and 5) the in-patient or out-patient rehabilitation (Table A1). Communicative validation and credibility was ensured during interviews by asking follow-up questions, by rephrasing, and by requesting details of positive and negative experiences (Brinkmann and Kvale, 2015). A debrief was conducted and revealed no negative experiences from participating in the interviews.

Data analysis

All interviews were transcribed verbatim by MS and a secretary otherwise unconnected to the project. Data were coded using NVivo software, v12.6.0 (QSR International, 2019) and analyzed thematically through systematic text condensation (STC), a pragmatic procedure based in phenomenology that allows researchers to search for the essence of a phenomenon (Malterud, 2012). When the analysis of data stopped revealing new themes, we considered saturation to be obtained and consequently concluded that the data gathered possessed adequate information power according to recommendations for qualitative research (Malterud, Siersma, and Guassora, 2016). The analysis followed four steps: 1) Overall impression – Each interview was read as a whole by MS and BN who independently suggested preliminary themes. Subsequently, workshops by MS, BN, and ECA who had read most of the interviews, were conducted and agreement was established; 2) Decontextualization – MS identified meaning units,

Table 3. Overview of informants.

ID	Gender	Age	Type of stroke	Location	Side	Premorbid employment status	NIHSS adm	In-patient rehab	Post stroke week at interview	Group
1	Male	55	Infarct	Parietal	Right	Employed	0	No	10	C
2	Male	75	infarct	Frontal	Left	Retired	2	No	9	C
3	Male	78	Infarct	Frontal/parietal	Right	Retired	3	Yes	9	C
4	Female	73	Infarct	Temporal/ parietal	Bilateral	Retired	11	Yes	18	I
5	Female	77	Infarct	Frontal/occipital	Bilateral	Retired	3	No	13	I
6	Male	58	Infarct	Brainstem	Left	Disability benefit	4	No	12	I
7	Male	75	Infarct	Parietal/occipital	Right	Retired	4	Yes	27	C
8	Male	77	Infarct	Parietal	Left	Retired	3	No	25	C
9	Female	79	Infarct	Parietal	Left	Retired	1	No	24	I
10	Female	82	Infarct	Frontal	Right	Retired	x	No	19	C
11	Male	75	Infarct	Parietal	Right	Retired	2	No	25	I
12	Female	39	Infarct	Temporal	Left side	Disability benefit	5	yes	19	I
13	Male	81	Hemmorage	Parietal/occipital	Right	Retired	14	yes	24	C
14	Female	71	Infarct	Capsula interna	Right	Retired	3	yes	15	C
15	Male	62	Infarct		Left	Disability benefit	4	yes	38	C
16	Male	74	Infarct	Temporal	Left	Retired	2	No	29	C
17	Male	75	Infarct	Lacunar	Bilateral	Retired	3	No	7	I

text fragments containing information about the research question in the transcribed material (Malterud and Malterud, 2012). Based on content, these were sorted into code groups. In this process we continuously moved between the meaning units and the research question to ensure that the code groups reflected the main themes in the material relevant to the research question; 3) Condensation – MS sorted the meaning units of each code group into subgroups and reduced the contents of each subgroup into a condensate written in first person and illustrated with a quote. Interpretations of condensates were discussed by MS, BN, ECA and HDJ; and 4) Synthesizing – Condensates were recontextualized as an analytical text in the third person, reviewed against the full transcript, and validated to ensure that the syntheses of the data reflected the original context. A category name replaced the previous code group name.

The final text was reviewed, and interpretations were informed by the existing literature, the theoretical framework, and the authors' varied professional experiences. An example of the analysis process is shown in Table 4. Two main categories were generated through the analysis.

Research team and reflexivity

Reflexivity was maintained throughout preparation, analysis, and writing by regularly discussing and challenging our established assumptions. In aiming for transparency we have adhered to the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014). The research team encompasses several areas of competency. BN, ECA, and MS are experienced in neurological physiotherapy, KBA is a medical doctor specializing in neurology, and HDJ is a philosopher and an expert in enactive theory. Knowledge about the patient group from clinical practice in physiotherapy (BN, ECA, MS) and medicine (KBA) provided the research team with positioned insight (Paulgaard, 1997) and warranted awareness of our preconceptions. This insight guided MS, BN, ECA, and KBA with creating the interview guide - a process in which a user representative who is part of the project group participated to ensure the inclusion of themes important to stroke survivors. The interview guide was assessed and adjusted after the first two interviews (Table A2). These interviews were evaluated in depth by BN to enhance the competency of MS as an interviewer with a developmental emphasis on asking open-ended questions and adequate follow-up questions. None of the members of the research team were personally or professionally acquainted with any of the informants.

Results

The 17 informants were between 39 and 82 years of age and had National Institute of Health Stroke Scale (NIHSS)[2] scores between 0–14 when admitted to hospital. 10 were allocated to the usual care group and 7 to the intervention group in the RCT (Table 3). The findings are organized in the two categories below, each presented as analytical text condensates supplemented with citations.

Table 4. Examples of the analysis process.

Step 1, preliminary themes	Step 2, examples of meaning units	Step 3, code group, sub-groups with headings and *condensates* (excerpts)			Step 4, category heading and *analytical text* (excerpts)
The stroke Waiting time Inactivity	*"As I was about to go into the movie theatre, suddenly I could not stand on that one leg"* *"I said to my wife -I think we should call now, call the doctor. Because something is not right"* *"I was lying there, I was to have an X-ray, an MRI and a CT scan. So, I laid there waiting for those. The days went by waiting for that sort of things"* *«How I would describe a day in the stroke unit? Well, I was in bed most of the time. That was it"*	A person vs a case	A silent earthquake *Suddenly I was unable to stand on my leg and I felt dizzy. What I noticed was that I could not speak or move like I wanted to. I could not butter the bread, I could not coordinate properly. We decided to call the doctor because something was not right. I decided to call the emergency number.*	Inactivity and waiting *There was no therapy in the stroke unit and no activities either. There wasn't much to do. A day in the stroke unit was long and boring as you just lay there waiting to see what they were doing next. I felt that my role was to stay in bed and be ready. I would have had capacity for more activity*	From an autonomous person to an assembly line object *The onset of the stroke was described as an awareness of sudden bodily changes and becoming unable to do something they usually took for granted. The participants made an active choice to seek help. When at the hospital the participants describe themselves as passive receivers of care. They describe a number of investigations and tests and that their main role was to stay put and be ready for the next investigation. Apart from assessments the participants describe being inactive for much of their time in the stroke unit.*

From an autonomous person to an assembly line object

The informants described the onset experience as an abrupt awareness of bodily change, one that manifested as a sudden inability to perform actions they normally took for granted, such as standing, driving, or other daily activities. As one informant put it:

> *What I noticed was that I could not speak, that I struggled to get the words out and say what I wanted. I was frustrated, because I couldn't speak and I could not move like I wanted to.* (ID 12)

Although the sudden loss of function was dramatic, most did not deem their situation an emergency, with the exception of three informants who fell and/or lost consciousness. Nine informants detailed changes that they did not associate with a stroke, despite some experiencing common symptoms, such as numbness or weakness in an extremity.

> *I actually don't know. It was a very strange sensation* [...]. *It was like, I just became a bit conscious of it. Almost like an inner voice saying there is something here.* [...] *I wasn't scared. I think now that I should have been, but it was so undramatic. So, I didn't call the emergency number until later that evening.* (ID 14)

Most felt a need to consult family or friends prior to contacting medical services. Two informants contacted emergency services themselves.

When admitted to hospital, informants figured themselves as passive receivers of treatment and care, subordinating their own actions to those of others in their descriptions. They trusted medical staff to provide updates on their condition and to make decisions on their behalf. In their stories, informants often described the days as long and boring, during which they simply remained in bed awaiting what they were doing next.

> *Well, I was lying there and it was: I was to have an x-ray, I was to have an MRI, and I was going for a CT-scan. So, I lay there waiting, the days went by waiting for those things.* (ID 6)

However, the close monitoring provided a sense of security and care. None reported any activities apart from investigations, assessments, monitoring, or meals in the stroke unit. One felt no commitment from the hospital in terms of facilitating activity and another said he would have had the capacity for more activity than what was offered. Only two informants reported that they needed the rest, as they felt ill or exhausted. Most informants described being able to get help when needed, but some opted to struggle on their own with personal care as independence was of particular importance to maintaining dignity. Most found the staff helpful and supportive, but one sensed that his reduced function was a burden.

> *The staff found it a bit stressful. When getting help on the ward, there was a lot of irritation, that I shouldn't spill water when I tried to wash and things like that. They thought I was clumsy. I mean, I needed help with lots of things, I spilled water on the floor. They were nice, but they got impatient.* (ID 7)

With regards to early rehabilitation in the hospital stroke unit, five informants said that they did not see any therapists during their stay, while ten saw a physiotherapist or a speech therapist. These encounters were frequently described as assessments rather than therapy.

The informants described a transition from being active agents and decision-makers in their own lives to passive receivers of care while in hospital after the stroke. The interactions with the multidisciplinary team were viewed as assessments, and descriptions of a coordinated multi-disciplinary approach to rehabilitation were lacking.

Emergent passivity versus participatory enablement

When discharged from hospital, seven of the informants that went directly home experienced the decision as sudden and premature. All but one described being told that they were to be discharged, some only a couple of hours before leaving the ward.

> *I wasn't part of the decision at all. I haven't asked my husband, but I guess the nurses and the doctors there thought it would be good. I thought it was too soon. I didn't say anything either. In a way, you just have to do as you´re being, well, as they tell you. But I can remember thinking: this has to be way too soon.* (ID 14)

Two informants did not feel ready to go home, while others looked forward to home comforts, such as a familiar bed or a home-cooked meal. One was unable to remember anything from the day of discharge. Some informants believed they were discharged because all the necessary assessments had been performed, and one did not think the stroke unit had more to offer as he was quite independent. The anticipation of physiotherapy, three times a week for twelve weeks, afforded a sense of security for those discharged to their home.

When discharged to a rehabilitation unit, experiences varied between being told about the transfer to being asked if they were interested in going. Three informants described having mixed feelings about rehabilitation, fearing the association with "elderly" people or the prospect of "becoming stuck" in an institution. Seven informants transferred to in-patient rehabilitation.

Experiences from the rehabilitation units were characterized by structure and team work. The informants positively highlighted being an active member in team meetings and goal-setting discussions.

> *It´s about how you´re being met* [. . .]. *That everyone in the team stops by for a talk, that you´re being asked questions about how you´re feeling, how you view your situation* [. . .]. *How you think and feel. That it shows that they care, that they take the time with the patient and focus on them.* (ID 15)

Informants valued the fact that staff were engaged on their behalf; this helped maintain both motivation and a sense that their care was the main focus. Developing independence in personal care was still a priority, and several informants worked hard toward this goal on their own. The informants had regular physiotherapy and occupational therapy while in the rehabilitation unit, and several had more than one session per day. Some performed independent exercises, but most had no other activities outside of formal therapy sessions.

Returning home after a stroke was a mixed experience for many informants, characterized by both relief and frustration. Some felt comfort in being able to relax and were eager to return to their families and daily routines. However, increased demands at home, such as elevated activity levels, parenting or caring responsibilities, led to the discovery of difficulties that were not obvious while in hospital, such as fatigue, balance problems, struggles with reading and writing, and mood changes.

> *I get more tired when walking now than just after the stroke, perhaps its normal. They talk about aftershocks after an earthquake, perhaps that's what it is, I guess it's the proper term.* (ID 13)

One said that her family found her to be angrier than before and that her speech problems led to misunderstandings and frustration. Another found it difficult to go out for coffee with his wife as he did before, because he “took in” all the noise in the café, which made him tired.

> *Yes, the invisible things. They tell me I look so well and that I´m just like before, and I think: you should have known, but they can´t see that the head suddenly will not work and that I have to lie down.* (ID 10)

These issues were more commonly raised among those being discharged directly home from the hospital stroke unit. Informants in the intermediate rehabilitation unit had the opportunity to gradually habituate with home visits or short leaves and thus felt more prepared for life at home.

All the informants participated in out-patient physiotherapy, and some received help with medications and showering from community nursing staff. None reported follow-up from any other professions. Despite the fact that several struggled with cognitive issues and fatigue that limited their participation in work, family life, or social activities, they were able to keep up with the intensive physiotherapy program. For some, the training sessions represented a positive element in their everyday life, while others saw it as a necessity, but not a particularly enjoyable one. Noticing signs of progress, such as increased strength or balance, was emphasized as positive and motivating.

> *I was very unsteady at first. Most of the exercises are difficult, but lately I have been looking forward to them. As I have felt how positive everything has been on my balance and strength, I have become more positive myself.* (ID 5)

At the time of the interview, several informants had finished their 12-week course and expressed a desire to continue their training. Several also performed independent exercises in addition to their physiotherapy treatment. For a period, some were provided with home exercises only, due to prohibitions against one-on-one physiotherapy treatments invoked during the Covid-19 pandemic. All found them difficult to execute, as they felt dependent upon the support and motivation provided by their physiotherapist.

Several informants lived in rural areas, and the post-stroke prohibition against driving for at least six months had significant consequences: impeding a return to work; increasing dependence upon family members; and for those living alone engendering social isolation and loneliness.

Discussion

One of the major findings of this study is that the culture and protocols of hospitals discourage active patient participation for people who have survived a stroke, despite its high importance during the period spent there. Patient participation fluctuates significantly throughout the course of a stroke and rehabilitation. Participation varies from patients being active agents, or autonomous subjects and decision-makers when a stroke hits, to becoming passive receivers of treatment and care while in hospital. Such changes may have lasting consequences after discharge. Furthermore, patient participation is characterized participatory enablement in the rehabilitation unit and in the community. Based on this, and informed by enactive theory, one may ask how participation depends on both individual autonomy and the context of interactions.

Autonomy: a prerequisite for patient participation – lost on the assembly line?

The immediate bodily changes attendant to stroke onset, which informants described mainly as an inability to perform familiar tasks, differ from those reported previously, as here they were less associated with distinct traumatic experiences (Connolly and Mahoney, 2018; Simeone et al., 2015). The autonomy of both individuals and interaction processes is by nature precarious and may be threatened by bodily changes, such as those caused by a stroke (De Jaegher, Peräkylä, and Stevanovic, 2016). A threat to an autonomous system such as the individual's identity demands adaptations involving a regulation of the relationship to the environment and internal states (Stilwell and Harman, 2019).

The fact that several informants opted to wait-and-see before seeking medical help is consistent with previous research in which laypersons did not categorize common stroke symptoms as a medical emergency (Li, Galvin, and Johnson, 2002). The informants report a distinct perception that 'something is not right.' This perception seems mainly triggered by the experience of "becoming unable" rather than by a recognition of specific neurological symptoms. Nevertheless, this triggers a need for adaptation to preserve identity (Stilwell and Harman, 2019) and this we posit is when the participants decide to get help. Excepting those who lost consciousness, the informants were still agents and active decision-makers in their own lives deciding if, how, and when to seek help.

Admission to hospital (i.e. becoming a patient) alters the roles and contexts connected to individual autonomy and changes the parameters of active participation. The rules and practices that are the basis for the autonomy of interactions between patients and health professionals are largely pre-coordinated, in the sense that they act together according to their roles in, or the conventions of, the institution (De Jaegher, Peräkylä, and Stevanovic, 2016). In the acute management of a stroke the inherent conventions of a hospital environment, both physical and social, reduce the autonomy of the individual into "a case" to be solved, like an item on an assembly line. This approach does however serve a purpose. Every minute counts when aiming to reduce damage to the brain, and the systematic efficiency and timeliness of measures can significantly optimize survival and function (Risitano and Toni, 2020). In this context there is meaning in letting the medical personnel take over to ensure bodily/identity protection. The cost is however that the autonomy of the individual is reduced, and our findings suggest that it may have prolonged consequences on participation.

The reduction of autonomy is evident in the way that patients submit to the hospital system and become passive receivers of treatment and care. The inactive and sedate time reported in our study is consistent with other investigations of patient activity levels in stroke units (Field et al., 2013; Normann, Arntzen, and Sivertsen, 2019; West and Bernhardt, 2012). Our results suggest that the level of activity, and thus active participation while in the stroke unit, remains unchanged despite concerns having been raised for many years. The long-term consequences on participation have not been previously highlighted. Additionally, descriptions of coordinated multidisciplinary early rehabilitation, involving active patient participation as outlined in several stroke guidelines (Lindsay et al., 2014; Norrving et al., 2018; Norwegian Directorate of Health, 2017) are lacking in our data. Despite caution being taken with regards to mobilization in the very early (< 24 hours) stages of a stroke (Langhorne et al., 2017) there are few reasons for further delay if the patient is medically stable and able to tolerate it (Bernhardt, Godecke, Johnson, and Langhorne, 2017; Winstein et al., 2016). This period of time is an important window of opportunity in terms of brain plasticity (Brodal, 2010; Langhorne and Ramachandra, 2020). As experiences and activities guide the brain's remodeling processes (Brodal, 2010), it is remarkable that the stroke units allow for inactivity. It is worth investigating whether the focus on acute care and its temporal demands along with the uncertainties surrounding the safety and amount of very early mobilization has displaced rehabilitation from the stroke unit more than is warranted.

The informants' descriptions of passivity and exclusion from decision-making are seemingly connected with the pre-coordinated patterns of these early and very institutionalized interactions. The informants did not question or oppose this praxis but accepted it and expressed that 'you just do as you're told.' The negative impact that paternalism in health care has on patient participation has been previously reported (Peoples, Satink, and Steultjens, 2011; Proot, ter Meulen, Abu-Saad, and Crebolder, 2007). The exception to the stated passivity is that the majority of informants made an active effort to be independent with regards to personal care. This indicates that such tasks are of great significance, and that dependence threatens one's sense of autonomy. Losing dignity in these situations was highlighted by the informants as negative experiences. Some expressed mixed feelings toward in-patient rehabilitation; they recognized it as beneficial to recovery but associated it with disability and institutionalization. From an enactive perspective, we believe these experiences are best explained in terms of vulnerability in social interactions where the socially-recognized self-image, or how the individual is viewed by others, is at stake or in danger of "losing face" (De Jaegher, Peräkylä, and Stevanovic, 2016; Goffman, 1983). De Jaegher, Peräkylä, and Stevanovic (2016) stated that *"our images as competent human actors, as men or women, or as incumbents of any other social identity are in the hands of our interaction partners."* It seems that in terms of autonomy the bodily changes caused by the stroke, the pre-coordination to the norms of behavior in a hospital, and the fear of losing face mutually reinforce the reduction in autonomy and thus diminish or somehow hollow out the basic and essential prerequisites for participation (Figure 1). While the initial reduction of autonomy may serve a purpose, the reduction in autonomy attendant to hospital culture should be conscientiously balanced against patient participation. In practical terms this means that wherever possible restrictions on participation should not be prolonged beyond the acute medical assessment and treatment.

Facilitation of participation through partnership in interactions

Rehabilitation is most effective when organized, from diagnosis to recovery, by coordinated stroke rehabilitation teams (Hartford, Lear, and Nimmon, 2019). For many, including those in our study, the stay in the stroke unit is the only period offering access to multidisciplinary treatment as such services are not commonly available in the community (Bernhardt, Godecke, Johnson, and Langhorne, 2017; Winstein et al., 2016). Lack of teamwork or poor communication between people who had a stroke and health professionals, may compromise and disempower the rehabilitation process with potential to diminish autonomous participation, confidence, and motivation (Hartford, Lear, and Nimmon, 2019; Luker et al., 2015; Voogdt-Pruis et al., 2019). This dynamic is affirmed by the fact that those informants who spent time in a rehabilitation unit between acute admission and return home described a smoother transition and saw themselves as better prepared for life at home. Our findings indicate that their time in the rehabilitation unit had strengthened their autonomy, making it easier to meet increasing demands and to participate actively in their life after discharge. We consider this a direct result of the facilitation of interdependent

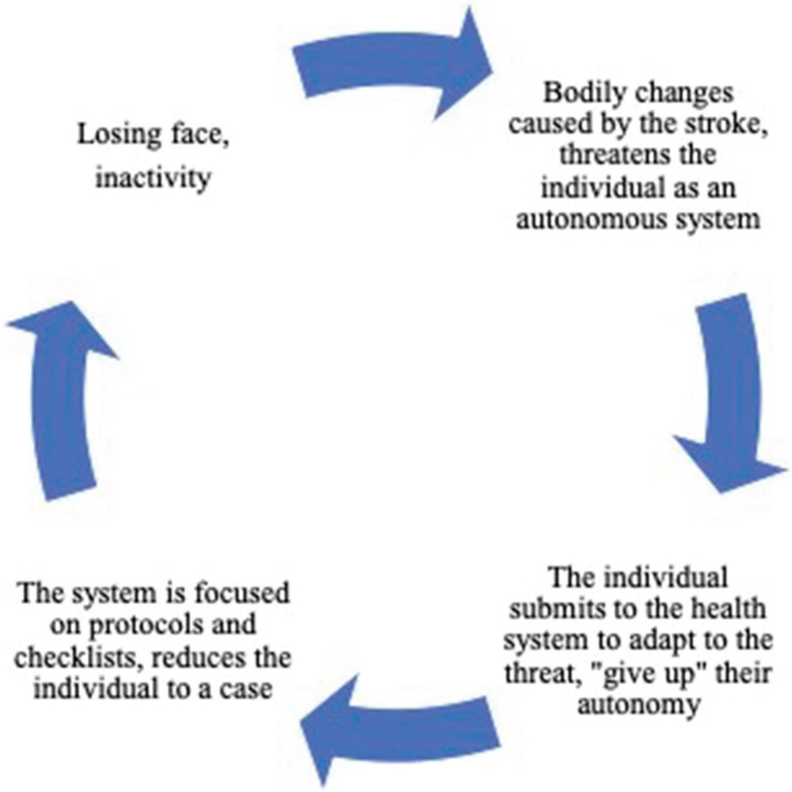


Figure 1. Factors that mutually reinforce reduction in autonomy in the acute stage.

autonomy, and thus of participation through coordinated teamwork in the rehabilitation unit. The informants described efforts targeted to the challenges specific to their daily lives, and they recalled being actively involved in decision-making and goal-setting. The pre-coordination of behavior in such a unit seems to be characterized by partnership and increased participation from patients in their interactions with health professionals. With what we call "partnership" here, we refer to the medical professional creating an opening in their interactions with patients for the latter's active participation in these interactions. Patient and physiotherapist are partners in the recovery journey, even if their contributions are necessarily asymmetrical, since one is a person in need and the other is an expert guide. To work properly, however, the rehabilitation process needs an opening to be made for active participation on the part of the health expert, and an uptake of this more active role on the part of the patient. From an enactive point of view, sense-making or meaning is generated between persons participating in interaction, and the partnership described between the patient and the staff at the rehabilitation unit reinforces the creation of meaningful action in therapy and activity. This view is supported by Luker et al. (2015) who stated that good communication and information during rehabilitation could directly foster autonomy through their positive influence on patient engagement. Among our informants, the support from the physiotherapist and the progress experienced in training crucially contributed to continuity and motivation during both in and outpatient treatment. The value of such a facilitator was struck into relief by the lockdown in March 2020 which occasioned an abrupt cessation of physiotherapy treatments. Many informants found it difficult to maintain exercises at home on their own. In this context there is no doubt a need to further explore precisely how physiotherapists function as motivators.

For those discharged directly home from the stroke unit, the transition represented a breach where resuming usual tasks at home and social interactions became difficult, even for those who felt they were ready. Our findings are in line with other studies that have found that both patients and caregivers feel unprepared for the transition from hospital to home (Faux et al., 2018; Gustafsson and Bootle, 2013). Other authors propose that rehabilitation needs, particularly in mild strokes, are commonly overlooked due to a lack of awareness of and sensitive assessment for cognitive problems, depression, or apathy (Faux et al., 2018). Several informants described that unexpected difficulties such as fatigue or cognitive problems, only surfaced after returning home. Some saw this as a deterioration, one which they were not helped in addressing since none received cognitive rehabilitation or counseling in the community. We interpret this less as an absolute deterioration than as a result of a discrepancy between the patient's actual and expected levels of autonomy; a discrepancy occasioned by the abrupt increase in demands and the lack of support when transitioning from "an object on the assembly line" or an individual in the hospital system to an active participant in the life world system.

Limitations

This study was conducted in two regions in Norway which somewhat limits the findings to the Scandinavian health care system. However, guidelines for stroke rehabilitation and patient participation are international, and applying concepts from enactive theory serves as a theoretical generalization (Malterud, 2015). We strategically sampled participants aiming for a broad representation. That said, we cannot rule out the possibility that participants who were excluded may have been able to add valuable contributions. Furthermore our sample is influenced by the criteria for participation in the RCT which omitted those with more severe disabilities. No specific cognitive or mental assessments except ruling out dementia were made. Due to the pandemic some interviews were delayed which might have introduced recall bias. However, our impression was that most participants recalled these events clearly.

Implications for practice

Health care professionals should be mindful of the importance of interdependent autonomy for participation, from the early stroke rehabilitation phase throughout the whole process of returning to local communities. This implies making activity and participation possible in the hospital setting and providing increased access to multidisciplinary support in the community. Attention to these notions is of particular importance for physiotherapists as it may motivate and facilitate activity for people who have survived a stroke throughout the whole rehabilitation continuum as an active partnership between patient and expert.

Conclusion

The present study elucidates how participation is important and how it is precarious and dependent upon both individual autonomy and social and institutional context. Bodily changes, the roles of both patient and health care professionals, and the hospital context mutually reinforce a reduction in autonomy after a stroke. These effects seem to last beyond discharge from hospital. Our results point to the usefulness of considering individual autonomy as a prerequisite for participation, a view that clarifies how partnership, activity, multidisciplinary support, and bodily improvements may strengthen autonomy and promote participation. This potential for promoting participation seems underutilized, particularly in the early phase of rehabilitation, but also in the community setting.

Notes

1. I-CoreDIST: Individualized Core activation combined with DISTal functional movement. I = individualized, Core = trunk, D = dual task, I = intensive, S = specific, stability, somatosensory stimulation, T = teaching, training.
2. An 11-item scale used to quantify the impairment caused by a stroke. A score of 0 indicates normal function while a higher score is indicative of some level of impairment. Maximum score is 42.

Acknowledgments

We would like to thank the individuals who participated in this study, the Nordland and Nord-Trøndelag Hospital Trusts for their support and for contributing to data collection, the participating hospitals and municipalities, and the user representative.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Northern Norway Regional Health Authority (Helse Nord RHF)

References

Bernhardt J, Godecke E, Johnson L, Langhorne P 2017 Early rehabilitation after stroke. Current Opinion in Neurology 30(1): 48–54. doi:10.1097/WCO.0000000000000404.

Brinkmann S, Kvale S 2015 InterViews: Learning the craft of qualitative research interviewing (3rd) ed. Thousand Oaks, California: Sage.

Brodal P 2010 The central nervous system. Structure and function. New York: Oxford University Press.

Connolly T, Mahoney E 2018 Stroke survivors' experiences transitioning from hospital to home. Journal of Clinical Nursing 27(21–22): 3979–3987. doi:10.1111/jocn.14563.

Cresswell JW, Poth CN 2018 Qualitative inquiry and research design. Choosing among five approaches. (4th), London: Sage Publications Ltd.

De Jaegher H, Di Paolo E 2007 Participatory sense-making: An enactive approach to social cognition. Phenomenology and the Cognitive Sciences 6(4): 485–507. doi:10.1007/s11097-007-9076-9.

De Jaegher H, Peräkylä A, Stevanovic M 2016 The co-creation of meaningful action: Bridging enaction and interactional sociology. Philosophical Transactions of the Royal Society London. Series B, Biological Sciences 371(1693): 20150378. doi:10.1098/rstb.2015.0378.

Di Paolo E, Rohde M, De Jaegher H 2010 Horizons for the enactive mind: Values, social interaction and play. In: Stewart J, Gapenne O, Di Paolo E (Eds) Enaction: Toward a new paradigm for cognitive science. Cambridge: Cambridge: MIT Press.

Elloker T, Rhoda AJ 2018 The relationship between social support and participation in stroke: A systematic review. African Journal of Disability 7: 357. doi:10.4102/ajod.v7i0.357.

Eriksson G, Baum MC, Wolf TJ, Connor LT 2013 Perceived participation after stroke: The influence of activity retention, reintegration, and perceived recovery. American Journal of Occupational Therapy 67(6): 131–138. doi:10.5014/ajot.2013.008292.

Ezekiel L, Collett J, Mayo NE, Pang L, Field L, Dawes H 2019 Factors associated with participation in life situations for adults with stroke: A systematic review. Archives of Physical Medicine and Rehabilitation 100(5): 945–955. doi:10.1016/j.apmr.2018.06.017.

Faux SG, Arora P, Shiner CT, Thompson-Butel A, Klein L 2018 Rehabilitation and education are underutilized for mild stroke and TIA sufferers. Disability and Rehabilitation 40(12): 1480–1484. doi:10.1080/09638288.2017.1295473.

Field MJ, Gebruers N, Shanmuga Sundaram T, Nicholson S, Mead G 2013 Physical activity after stroke: A systematic review and meta-analysis. International Scholarly Research Notices 2013: 464176.

Foley EL, Nicholas ML, Baum CM, Connor LT 2019 Influence of environmental factors on social participation post-stroke. Behavioural Neurology 2019: 2606039. doi:10.1155/2019/2606039.

Fuchs T, De Jaegher H 2009 Enactive intersubjectivity: Participatory sense-making and mutual incorporation. Phenomenology and the Cognitive Sciences 8(4): 465–486. doi:10.1007/s11097-009-9136-4.

Goffman E 1983 The interaction order: American Sociological Association, 1982 Presidential Address. American Sociological Review 48(1): 1–17. doi:10.2307/2095141.

Gustafsson L, Bootle K 2013 Client and carer experience of transition home from inpatient stroke rehabilitation. Disability and Rehabilitation 35(16): 1380–1386. doi:10.3109/09638288.2012.740134.

Hartford W, Lear S, Nimmon L 2019 Stroke survivors' experiences of team support along their recovery continuum. BMC Health Services Research 19(1): 723. doi:10.1186/s12913-019-4533-z.

Hay ME, Connelly DM, Kinsella EA 2016 Embodiment and aging in contemporary physiotherapy. Physiotherapy Theory and Practice 32(4): 241–250. doi:10.3109/09593985.2016.1138348.

Jones F, Gombert K, Honey S, Cloud G, Harris R, Macdonald A, McKevitt C, Robert G, Clarke D 2021 Addressing inactivity after stroke: The Collaborative Rehabilitation in Acute Stroke (CREATE) study. International Journal of Stroke 16(6): 669–682. doi:10.1177/1747493020969367.

Lahelle AF, Øberg GK, Normann B 2020 Physiotherapy assessment of individuals with multiple sclerosis prior to a group intervention – A qualitative observational and interview study. Physiotherapy Theory and Practice 36(3): 386–396. doi:10.1080/09593985.2018.1488022.

Langhorne P, Ramachandra S 2020 Organised inpatient (stroke unit) care for stroke: Network meta-analysis. Cochrane Database of Systematic Reviews 4: CD000197. doi:10.1002/14651858.CD000197.pub4.

Langhorne P, Wu O, Rodgers H, Ashburn A, Bernhardt J 2017 A Very Early Rehabilitation Trial after stroke (AVERT): A phase III, multicentre, randomised controlled trial. Health Technology Assessment 21(54): 1–120. doi:10.3310/hta21540.

Légaré F, Adekpedjou R, Stacey D, Turcotte S, Kryworuchko J, Graham ID, Lyddiatt A, Politi MC, Thomson R, Elwyn G et al. 2018 Interventions for increasing the use of shared decision making by healthcare professionals. Cochrane Database of Systematic Reviews 7: CD006732. doi:10.1002/14651858.CD006732.pub4.

Li J, Galvin HK, Johnson SC 2002 The “prudent layperson” definition of an emergency medical condition. American Journal of Emergency Medicine 20(1): 10–13. doi:10.1053/ajem.2002.30108.

Lindsay P, Furie KL, Davis SM, Donnan GA, Norrving B 2014 World Stroke Organization Global Stroke Services Guidelines and Action Plan. International Journal of Stroke 9(Suppl A100): 4–13. doi:10.1111/ijs.12371.

Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J 2015 Stroke Survivors‘ Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies. Archives of Physical Medicine and Rehabilitation 96(9): 1698–1708. doi:10.1016/j.apmr.2015.03.017.

Mallinson TP, Hammel JP 2010 Measurement of participation: Intersecting person, task, and environment. Archives of Physical Medicine and Rehabilitation 91(9): 29–33. doi:10.1016/j.apmr.2010.04.027.

Malterud K 2012 Systematic text condensation: A strategy for qualitative analysis. Scandinavian Journal of Public Health 40 (8): 795–805. doi:10.1177/1403494812465030.

Malterud K 2015 Theory and interpretation in qualitative studies from general practice: Why and how?. Scandinavian Journal of Public Health 44(2): 120–129. doi:10.1177/1403494815621181.

Malterud K, Siersma VD, Guassora AD 2016 Sample size in qualitative interview studies: Guided by information power. Qualitative Health Research 26(13): 1753–1760. doi:10.1177/1049732315617444.

Martinez-Pernia D 2020 Experiential Neurorehabilitation: A Neurological Therapy Based on the Enactive Paradigm. Frontiers in Psychology 11: 924. doi:10.3389/fpsyg.2020.00924.

Normann B 2020 Facilitation of movement: New perspectives provide expanded insights to guide clinical practice. Physiotherapy Theory and Practice 36(7): 769–778. doi:10.1080/09593985.2018.1493165.

Normann B, Arntzen EC, Sivertsen M 2019 Comprehensive core stability intervention and coordination of care in acute and subacute stroke rehabilitation - A pilot study. European Journal of Physiotherapy 21(4): 187–196. doi:10.1080/21679169.2018.1508497.

Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, Kutluk K, Mikulik R, Wardlaw J, Richard E et al. 2018 Action plan for stroke in Europe 2018-2030. European Stroke Journal 3(4): 309–336. doi:10.1177/2396987318808719.

Norwegian Directorate of Health 2017 Nasjonal Faglig Retningslinje for Behandling og Rehabilitering ved Hjerneslag [National guidelines for treatment and rehabilitation in stroke]. Oslo, Norway. https://helsedirektoratet.no/retningslinjer/hjerneslag

O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA 2014 Standards for reporting qualitative research: A synthesis of recommendations. Academic Medicine 89(9): 1245–1251. doi:10.1097/ACM.0000000000000388.

Palstam A, Sjödin A, Sunnerhagen KS 2019 Participation and autonomy five years after stroke: A longitudinal observational study. PLoS One 14(7): e0219513. doi:10.1371/journal.pone.0219513.

Paolucci S, Di Vita A, Massicci R, Traballesi M, Bureca I, Matano A, Iosa M, Guariglia C 2012 Impact of participation on rehabilitation results: A multivariate study. European Journal of Physical and Rehabilitation Medicine 48(3): 455–466.

Paulgaard G 1997 Feltarbeid i egen kultur: Innenfra, utefra eller begge deler? [Fieldwork in their own culture: From within, from outside or both?. In: Fossåskåret E, Fuglestad OL, Aase TH (Eds) Metodisk Feltarbeid. Produksjon og Tolkning av Kvalitative Data [Methodical Fieldwork. Production and Interpretation of Qualitative Data], pp. 70–93. Oslo: Universitetsforlaget.

Peoples H, Satink T, Steultjens E 2011 Stroke survivors’ experiences of rehabilitation: A systematic review of qualitative studies. Scandinavian Journal of Occupational Therapy 18(3): 163–171. doi:10.3109/11038128.2010.509887.

Phipps MS, Cronin CA 2020 Management of acute ischemic stroke. British Medical Journal 368: l6983. doi:10.1136/bmj.l6983.

Proot IM, ter Meulen RH, Abu-Saad HH, Crebolder HF 2007 Supporting stroke patients’ autonomy during rehabilitation. Nursing Ethics 14(2): 229–241. doi:10.1177/0969733007073705.

Risitano A, Toni D 2020 Time is brain: Timing of revascularization of brain arteries in stroke. European Heart Journal Supplements 22(Supplement_L): L155–L159. doi:10.1093/eurheartj/suaa157.

Simeone S, Savini S, Cohen MZ, Alvaro R, Vellone E 2015 The experience of stroke survivors three months after being discharged home: A phenomenological investigation. European Journal of Cardiovascular Nursing 14(2): 162–169. doi:10.1177/1474515114522886.

Stilwell P, Harman K 2019 An enactive approach to pain: Beyond the biopsychosocial model. Phenomenology and the Cognitive Sciences 18(4): 637–665. doi:10.1007/s11097-019-09624-7.

Thompson E 2007 Mind in Life: Biology, Phenomenology, and the Sciences of Mind. Cambridge, Massachusetts: The Belknap Press of Harvard University Press.

Varela FJ, Thompson E, Rosch E 2016 The Embodied Mind: Cognitive Science and Human Experience (6th) ed. Cambridge, Massachusetts: MIT Press.

Voogdt-Pruis HR, Ras T, van der Dussen L, Benjaminsen S, Goossens PH, Raats I, Boss G, van Hoef EF, Lindhout M, Tjon-A-Tsien MR et al. 2019 Improvement of shared decision making in integrated stroke care: A before and after evaluation using a questionnaire survey. BMC Health Services Research 19(1): 936. doi:10.1186/s12913-019-4761-2.

West T, Bernhardt J 2012 Physical activity in hospitalised stroke patients. Stroke Research and Treatment 2012: 813765. doi:10.1155/2012/813765.

Winstein CJ, Stein J, Arena R, Bates B, Cherney LR, Cramer SC, Deruyter F, Eng JJ, Fisher B, Harvey RL et al. 2016 Guidelines for adult stroke rehabilitation and recovery: A guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke 47(6): e98–e169. doi:10.1161/STR.0000000000000098.

World Health Organization 2013 How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organization.

Appendix 1

Table A1. Initial interview guide.

Sequence	Theme	Post-revision: Opening question ● Possible questions and probes
Opening	Aim and plan for the interview,	Plan for the interview
		Aim, explanation of why we are conducting interviews, the type of knowledge they will generate. That knowledge of both positive and negative experiences may contribute in the development of services. Disclosure of interviewers' role as a researcher and physiotherapist (not involved in the treatment of any participants in this study); that in order to improve clinical practice we need to know both what is perceived as meaningful and what is not.
Body	The acute situation	Can you tell me about the day you had your stroke? Is there anything you remember particularly well?
		● What changed in your body
		● What did you feel, what did you think?
		● Were you with someone? How did they react?
		Is there anything you remember especially well from the first day in hospital?
		● Positive, negative experiences, why was this important to you?
	Participation in daily activities in hospital	Can you describe a normal day in the stroke unit?
		● Can you tell me about your first memory from the stroke unit?
		● Can you describe the atmosphere?
		● Did you need help at all? Can you describe the help you got? How did you feel about it?
		● Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you?
		● How do you feel about the contents of a usual day in the stroke unit/rehabilitation unit? What was particularly good/not great? What would you improve?
		What are your thoughts about the care you received and how it was tailored to your needs?
	Transfer from hospital to rehabilitation unit or home Transfer from rehabilitation unit to home	Can you tell me about the day you were discharged from the hospital/rehabilitation unit to the rehabilitation unit or home?
		● What were your expectations?
		● When did you learn about the discharge?
		● What were your feelings about being discharged?
		● What role did you have in planning when the discharge was going to happen?
		● Was anyone else involved in this decision
		● Were any preparations done? What were they and who was involved?
		● How did you feel about being discharged? (ready/prepared)
		● Can you tell me about that day, from before leaving the hospital? What was your expectations, feelings, thoughts?
		● What is the first thing you remember from coming to the rehabilitation unit/home? (good, challenging)
	Daily activities at home	Can you tell me about a normal day at home?
		● Describe your routines, need for help and access to help if needed, thoughts and reflections around this.
		● What kind of therapy/training sessions do you have on a regular basis? How do you get to those? How do you feel about these?
		● Do you exercise/are you active outside of your regular therapy/training sessions?
		● What else do you do in a normal day?
	In-patient/out-patient rehabilitation	What is the first thing you remember from the rehabilitation unit?
		Can you describe a normal day in the rehabilitation unit?
		● Can you describe the atmosphere?
		● Did you need help at all? Can you describe the help you got? How did you feel about it?
		● Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you?
		How do you feel about the contents of a usual day in the rehabilitation unit? What was particularly good/not great? Why was this important to you? What would you have wanted done differently?
		Can you tell me about the rehabilitation you received at home?
		● Physiotherapy, Occupational therapy, Speech therapy, other
		● What was most important to you in rehabilitation (body function, activity, participation levels)? Why was this particularly important? Was there anything that you did not find useful? What was that? What made you feel that way about it?
		● In what way were what you did in rehabilitation useful with regards to your difficulties.
		● How were plans for the sessions made
Closure	Rehabilitation course	Did we leave out something that was important to you? Would you like to add something?
		If you were able to change something about your rehabilitation course, what would that be?
	Interview	Summary – How did you find participating in this interview?

Appendix 2

Table A2. Amended interview guide.

Sequence	Theme	Pre-revision: Opening question ● Possible questions and probes	Post-revision: Opening question ● Possible questions and probes
Opening	Aim and plan for the interview,	Plan for the interview Aim, explanation of why we are conducting interviews, the type of knowledge they will generate. That knowledge of both positive and negative experiences may contribute in the development of services.	Plan for the interview Aim, explanation of why we are conducting interviews, the type of knowledge they will generate. That knowledge of both positive and negative experiences may contribute in the development of services. Disclosure of interviewers' role as a researcher and physiotherapist (not involved in the treatment of any participants in this study); that in order to improve clinical practice we need to know both what is perceived as meaningful and what is not.
Body	The acute situation	Can you tell me about the day you had your stroke? Where were you and how did you feel (bodily changes)? ● Is there something you remember particularly well? ● How did you feel, what did you think?	Can you tell me about the day you had your stroke? Is there anything you remember particularly well? ● What changed in your body ● What did you feel, what did you think? ● Were you with someone? How did they react?
		Is there anything you remember especially well from the first day? ● How did you get to the hospital? ● Positive, negative experiences	Is there anything you remember especially well from the first day in hospital? ● Positive, negative experiences, why was this important to you?
	Participation in daily activities in hospital	Can you describe a normal day in the stroke unit? ● What is the first thing you remember from the stroke unit? ● Your room, the atmosphere, access to help? ● What were your opportunities for actively participating in daily activities/routines, such as personal hygiene, meals. Where were such activities carried out? What are your thoughts and feelings around these situations? Should anything have been done differently? ● Who decided how daily activities were carried out? ● Where did you have your meals? How did you get to your meals	Can you describe a normal day in the stroke unit? ● Can you tell me about your first memory from the stroke unit? ● Can you describe the atmosphere? ● Did you need help at all? Can you describe the help you got? How did you feel about it? ● Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you? ● How do you feel about the contents of a usual day in the stroke unit/rehabilitation unit? What was particularly good/not great? What would you improve?
		Was the treatment you received in the stroke unit/rehabilitation unit tailored to your needs?	What are your thoughts about the care you received and how it was tailored to your needs?
	Transfer from hospital to rehabilitation unit or home Transfer from rehabilitation unit to home	Can you tell me about the day you were discharged from the hospital/rehabilitation unit to the rehabilitation unit or home? ● What were your expectations? ● When did you learn about the discharge? ● What were your feelings about being discharged? ● What role did you have in planning when the discharge was going to happen? ● Was anyone else involved in this decision ● Were any preparations done? What were they and who was involved? ● How did you feel about being discharged? (ready/prepared) ● Can you tell me about that day, from before leaving the hospital? What was your expectations, feelings, thoughts? ● What is the first thing you remember from coming to the rehabilitation unit/home? (good, challenging) ● Was there anything about the transfer from hospital to the rehabilitation unit/home that could have been done differently?	Unchanged

(*Continued*)

Table A2. (Continued).

Sequence	Theme	Pre-revision: Opening question ● Possible questions and probes	Post-revision: Opening question ● Possible questions and probes
	Daily activities at home	Can you tell me about a normal day at home? ● Describe your routines, need for help and access to help if needed, thoughts and reflections around this. ● What kind of therapy/training sessions do you have on a regular basis? How do you get to those? How do you feel about these? ● Do you exercise/are you active outside of your regular therapy/training sessions? ● What else do you do in a normal day?	Unchanged
	In-patient/out-patient rehabilitation	What is the first thing you remember from the rehabilitation unit? Can you describe a normal day in the rehabilitation unit? ● Your room, the atmosphere, access to help? ● What were your opportunities for actively participating in daily activities/routines, such as personal hygiene, meals. Where were such activities carried out? What are your thoughts and feelings around these situations? Should anything have been done differently? ● Who decided how daily activities were carried out? Can you tell me about the rehabilitation you received at home? ● Physiotherapy, Occupational therapy, Speech therapy, other ● What was most important to you in rehabilitation (body function, activity, participation levels)? Why was this particularly important? Was there anything that you did not find useful? What was that? What made you feel that way about it? ● In what way were what you did in rehabilitation useful with regards to your difficulties? ● How was the content for the sessions decided upon?	What is the first thing you remember from the rehabilitation unit? Can you describe a normal day in the rehabilitation unit? ● Can you describe the atmosphere? ● Did you need help at all? Can you describe the help you got? How did you feel about it? ● Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you? How do you feel about the contents of a usual day in the rehabilitation unit? What was particularly good/not great? Why was this important to you? What would you have wanted done differently? Can you tell me about the rehabilitation you received at home? ● Physiotherapy, Occupational therapy, Speech therapy, other ● What was most important to you in rehabilitation (body function, activity, participation levels)? Why was this particularly important? Was there anything that you did not find useful? What was that? What made you feel that way about it? ● In what way were what you did in rehabilitation useful with regards to your difficulties. ● How were plans for the sessions made
Closure	Rehabilitation course	Did we leave out something that was important to you? Would you like to add something? If you were able to change something about your rehabilitation course, what would that be?	Unchanged
	Interview	Summary How did you find participating in this interview?	Unchanged

Paper III

Sivertsen, M., De Jaegher, H., Arntzen, E. C., Alstadhaug, K. B., & Normann, B. (2022). Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke: A qualitative study. *Physiotherapy research international: the journal for researchers and clinicians in physical therapy*, *27*(3), e1948. https://doi.org/10.1002/pri.1948

Received: 13 September 2021 | Revised: 20 December 2021 | Accepted: 24 February 2022

DOI: 10.1002/pri.1948

RESEARCH ARTICLE

WILEY

Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke: A qualitative study

Marianne Sivertsen[1,2] | **Hanne De Jaegher**[3,4] | **Ellen Christin Arntzen**[2,5] | **Karl Bjørnar Alstadhaug**[1,6] | **Britt Normann**[2,5]

[1]Department of Health and Care Sciences, UiT The Arctic University of Norway, Tromsoe, Norway

[2]Nordland Hospital Trust, Bodoe, Norway

[3]Department of Philosophy, University of the Basque Country, San Sebastián, Spain

[4]School of Psychology, University of Sussex, Brighton, UK

[5]Faculty of Nursing and Health Sciences, Nord University, Bodoe, Norway

[6]Department of Clinical Medicine, UiT The Arctic University of Norway, Tromsoe, Norway

Correspondence

Marianne Sivertsen, Nordland Hospital Trust, PB 1480, N-8092 Bodoe, Norway.
Email: marianne.sivertsen2@nordlandssykehuset.no

Funding information

Helse Nord RHF

Abstract

Background and Purpose: Physiotherapy, with an emphasis on high intensity, individually tailored, and person-centered treatment, is an effective route for recovery after a stroke. No single approach, however, has been deemed paramount, and there is limited knowledge about the patient experience of assessment, goal-setting, and treatment in physiotherapy. In this study, we seek to report patient experiences of I-CoreDIST—a new physiotherapy intervention that targets recovery—and those of usual care. The purpose is to investigate how individuals with stroke experience the bodily and interactive course of physiotherapy during their recovery process.

Methods: A qualitative study, nested within a randomized controlled trial, consisting of in-depth interviews with 19 stroke survivors who received either I-CoreDIST or usual care. Data were analyzed using systematic text condensation, and this analysis was informed by enactive theory.

Results: Interaction with the physiotherapist, which was guided by perceived bodily changes, fluctuated between being, on the one hand, formal/explicit and, on the other, tacit/implicit. The experiences of participants in the intervention group and the usual care group differed predominantly with regards to the content of therapy sessions and the means of measuring progress; divergences in levels of satisfaction with the treatment were less pronounced. The perception of positive bodily changes, as well as the tailoring of difficulty and intensity, were common and essential features in generating meaning and motivation. An embodied approach seemed to facilitate sense-making in therapy situations. In the interaction between the participants and their physiotherapists, trust and engagement were important but also multifaceted, involving both interpersonal skills and professional expertise.

Conclusion: The embodied nature of physiotherapy practice is a source for sense-making and meaning-construction for patients after a stroke. Trust in the physiotherapist, along with emotional support, is considered essential. Experiencing progress and individualizing approaches are decisive motivators.

KEYWORDS
enactive theory, interaction, physiotherapy, qualitative research, stroke

1 | INTRODUCTION

Physiotherapy is effective for the recovery of function and mobility after a stroke (Pollock et al., 2014). High-dose and high-intensity training, together with selecting treatment components based on an individual assessment, are recommended as a foundation for implementing evidence-based treatment (Pollock et al., 2014; Saunders et al., 2020). Several treatment approaches exist, but no single one has been elevated as superior to any other (Bernhardt et al., 2017; Pollock et al., 2014). Additionally, patient experiences of physiotherapy assessment after a stroke are insufficiently investigated (Pak et al., 2015). New interventions promoting recovery, as opposed to compensatory strategies, are called for (Frykberg & Vasa, 2015; Levin & Demers, 2020). I-CoreDIST[1] is a recent, individualized intervention aimed at recovery. For people with multiple sclerosis, it has proved effective (Arntzen, Straume, et al., 2019) and meaningful in group settings (Arntzen, Oberg, et al., 2019). It is also feasible in individual post-stroke rehabilitation (Normann et al., 2019). How this intervention is perceived by individuals with sub-acute stroke has not yet been investigated. Moreover, there is generally limited knowledge about patient perspectives on the content and impact of usual care physiotherapy after a stroke. In the development of new interventions, it is vital to consider user perspectives on what constitutes engagement and on how the intervention is best implemented in a clinical setting (MacDonald et al., 2013).

Individually tailored approaches and person-centered services, prioritizing patient participation in goal-setting and decision-making, are widely endorsed (Kjellstrom et al., 2007; Pollock et al., 2014; Yun & Choi, 2019). However, difficulties with implementation are often reported (Busetto et al., 2020; Lloyd et al., 2018), and thus more user-based knowledge regarding individualization, goal-setting, and decision-making in post-stroke physiotherapy is needed.

Previous research has highlighted expectations of functional improvement and increased levels of activity as reasons why patients appreciate physiotherapy (Pound et al., 1994). The physiotherapist is often viewed as someone who provides knowledge, whose attitude is essential for motivation (Jansson & Carlsson, 2021; Kelly et al., 2020), and a source of faith and hope (Pound et al., 1994). Interestingly, Peiris et al. (2012) found that patients value the interaction with the physiotherapist more than the content of the sessions.

Interaction with others creates meaning (Fuchs & De Jaegher, 2009), and such meaningful engagement can significantly shape the outcome of stroke rehabilitation (Galvin et al., 2009; Levin & Demers, 2020). Indeed, behavioral neuroscience and contemporary models of motor learning suggest that meaningful activities targeting user goals are essential in recovering function (Danzl et al., 2012; Levin & Demers, 2020; Newell & Verhoeven, 2017). The interaction between patient and physiotherapist is, by nature, inherently embodied (Roenn-Smidt et al., 2020), meaning that the body is conceived as experiencing and expressive simultaneously as being a biological organism (Merleau-Ponty, 2008). In physiotherapy, interaction and clinical skills are interwoven and embodied, evolving through words, gestures, and hands-on interactions (Normann, 2020). Given the embodied and interactive nature of physiotherapy, any investigative model must attend to the interaction between physiotherapist and patient, as well as to their motivations, bodily states, capacities, skills, and needs.

Enactive theory in cognitive science draws on phenomenology and dynamic systems theory, viewing the interactions between mind, body, and the environment as inseparably intertwined in mental processes (Thompson, 2007). We propose that this theory is suited to illuminate significant aspects of the interaction between patient and physiotherapist, as it encompasses the way that a person's bodily needs, motivations, and constraints determine how they make sense of their interactions with the world (Thompson, 2007). Two of the most relevant technical concepts here are agency and participatory sense-making. Agency is defined as a person's adaptive capacity to regulate their interactions with the environment according to self-generated norms. Cognition, or sense-making, is defined as a person's participation in what matters to them (Fuchs & De Jaegher, 2009). Socially, people engage in participatory sense-making; if making sense of the world is deeply determined by how one moves around in it, then engaging with others—including when moving together—means that sense-making activities are partly co-determined. Thus, how people understand the world, themselves, and each other—including, what it means to have suffered a stroke and to engage in physiotherapy for recovery—is determined through embodied participation.

The aim of this study was to identify user experiences of I-CoreDIST and of usual care in post-stroke physiotherapy by addressing the following research question: How do individuals with stroke experience the bodily and interactive course of physiotherapy during their recovery?

2 | METHODS

2.1 | Design

Based on the research question, a qualitative interview within a phenomenological hermeneutic framework was chosen, as it allows knowledge to be derived from lived experiences (Cresswell & Poth, 2018; Malterud, 2015).

2.2 | Context of the study

This interview study was nested within a randomized controlled trial (RCT; Figure 1; ClinicalTrials.gov Identifier: NCT04069767), comparing a new intervention, I-CoreDIST, against usual care (Table 1). Data were collected between December 2019 and December 2020. Inclusion and exclusion criteria are outlined in Table 2. The first (MS), third (ECA), and last (BN) authors have developed the I-CoreDIST intervention. They are, together with the fourth author (KBA) investigators in the RCT but have not been involved in the treatment of any participants.

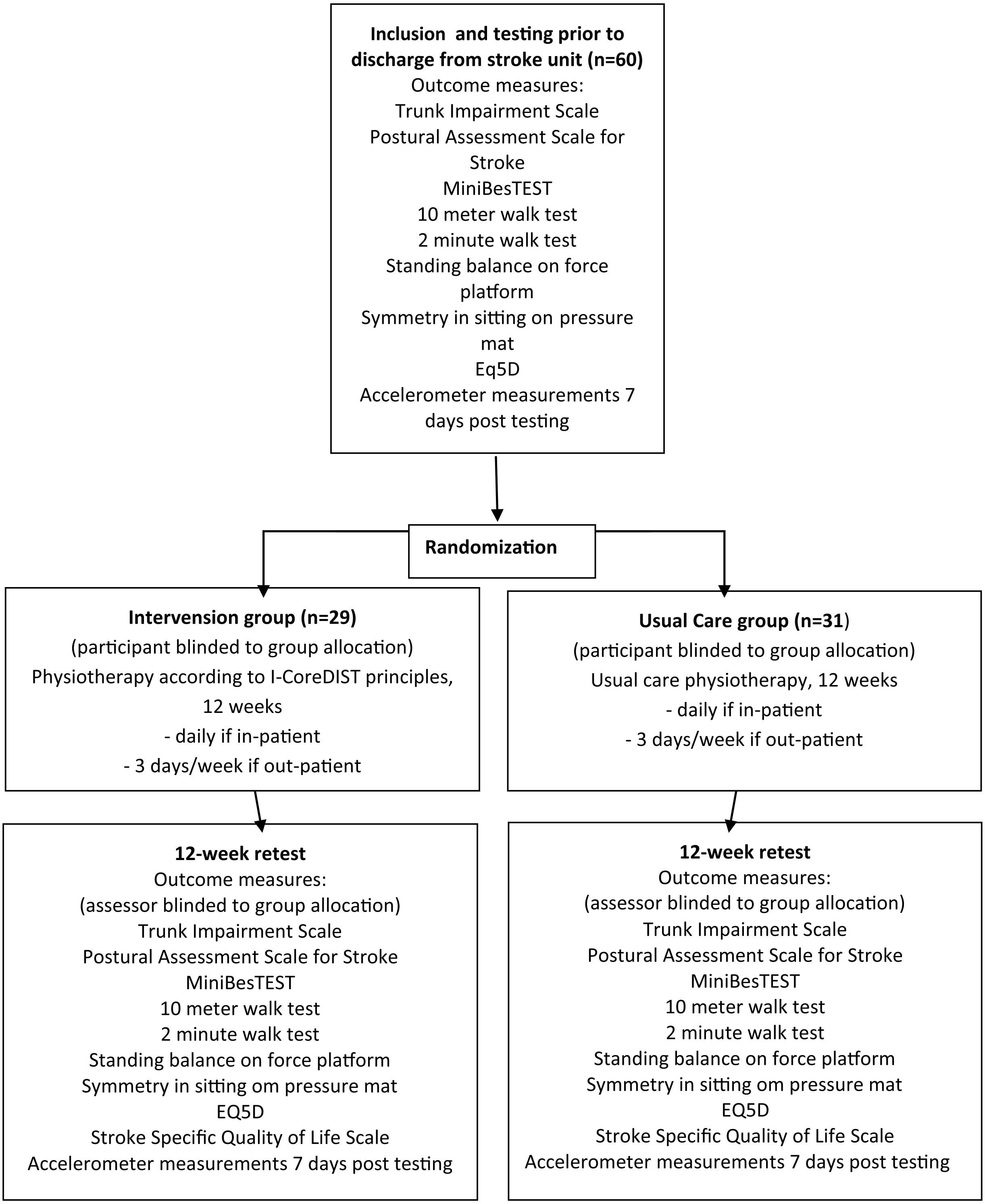


FIGURE 1 Flowchart of the randomized controlled trial

TABLE 1 Intervention (I-CoreDIST) and usual care

Intervention	Usual care
Physiotherapy daily if in-patient or 3 days/week if outpatient.	Physiotherapy daily if in-patient or 3 days/week if outpatient.
12-week follow-up	12-week follow-up
Structure for assessment	No guidelines regarding physiotherapy approach
Clinical reasoning charts	
Booklet containing 44 illustrated exercises, each with five levels of difficulty	

TABLE 2 Inclusion and exclusion criteria for the RCT

Inclusion criteria	Exclusion criteria
Admitted to the stroke unit with confirmed stroke	Unable to cooperate in physiotherapy
Age: 18–85	Previously known dementia preventing participation in physiotherapy
Premorbid modified ranking scale 0–3	Ongoing substance-abuse
Able to sit unsupported for 10 s	Other severe disease preventing rehabilitation
Trunk impairment Scale—Norwegian version score <15	

2.3 | Participants and sample

Recruitment was conducted at two stroke units. We purposively sampled 19 participants (ID1–ID19) from both the intervention group (IG) and the usual care group (UC), aiming to detect perceptions of content and to identify differences and similarities. To ensure a diverse sample, participants were drawn from a variety of geographical locations, and they differ in gender, age, stroke location, and level of disability but with no severe aphasia. The gender composition differed between the two groups with 20% females in the UG and 67% in the IG. Furthermore, half of the patients in the UG had inpatient rehabilitation compared to only one third in the IG. Median age (75 years) and NIHSS at admission (3), were the same in both groups. Participants' characteristics are shown in Table 3.

We initially aimed at interviewing participants 6–12 weeks after inclusion but encountered considerable delays in recruitment caused by the COVID-19 pandemic. Due to reduced capacity for testing at the hospitals and a ban on out-patient physiotherapy treatment, inclusion was stopped between March and June 2020. To maintain progress in the project, participants were sampled from the initial 40 participants in the RCT, rather than from the full sample (recruited between September 2019 and September 2021). As a result, some were interviewed up to 38 weeks after inclusion. When analysis did not reveal new themes, we concluded that saturation was reached, and that the data possessed adequate information power (Malterud et al., 2016).

2.4 | Data collection

The interviews were conducted by MS and lasted between 20 and 91 min, constituting a total time of 840 min. The first six interviews were face-to-face, while the rest were, due to COVID-19 restrictions, performed over the phone, using a speakerphone and a digital recorder. A theme-based interview guide with open-ended questions initiated reflections on: (1) the content and experience of physiotherapy, (2) the participation in decision-making and goal-setting, and (3) the interaction/relationship with the physiotherapist. Communicative validation was ensured by asking follow-up questions, rephrasing, and requesting details of positive and negative experiences (Brinkmann & Kvale, 2015). A debrief revealed no negative experiences.

2.5 | Data analysis

All interviews were transcribed verbatim by MS and a secretary not otherwise connected to the project. Data were coded using NVivo software, v12.6.0 (QSR International, 2019) and analyzed through systematic text condensation, a process of decontextualization and recontextualization (Malterud, 2012). The analysis followed four steps: (1) MS read every interview, while ECA and BN reviewed a selection to develop an overall impression. This process was followed by discussions on preliminary themes, (2) MS identified meaning units containing information about the research question and organized

TABLE 3 Overview of participants

ID	Gender	Age	Type of stroke	Location	Side	Premorbid employmentstatus	NIHSS at admission	In-patient rehabilitation	Post-stroke week at interview	Group
1	Male	55	Infarct	Parietal	Right	Employed	0	No	10	C
2	Male	75	Infarct	Frontal	Left	Retired	2	No	9	C
3	Male	78	Infarct	Frontoparietal	Right	Retired	3	Yes	9	C
4	Female	73	Infarct	Temporoparietal	Bilateral	Retired	11	Yes	18	I
5	Female	77	Infarct	Frontal and occipital	Bilateral	Retired	3	No	13	I
6	Male	58	Infarct	Brainstem	Left	Disability benefit	4	No	12	I
7	Male	75	Infarct	Parietooccipital	Right	Retired	4	Yes	27	C
8	Male	77	Infarct	Parietal	Left	Retired	3	No	25	C
9	Female	79	Infarct	Parietal	Left	Retired	1	No	24	I
10	Female	82	Infarct	Frontal	Right	Retired	NA	No	19	C
11	Male	75	Infarct	Parietal	Right	Retired	2	No	25	I
12	Female	39	Infarct	Temporal	Left	Disability benefit	5	Yes	19	I
13	Male	81	Haemorrhage	Parietooccipital	Right	Retired	14	Yes	24	C
14	Female	71	Infarct	Internal capsule	Right	Retired	3	Yes	15	C
15	Male	62	Infarct	NA	Left	Disability benefit	4	Yes	38	C
16	Male	74	Infarct	Temporal	Left	Retired	2	No	29	C
17	Male	75	Infarct	Corona radiata	Bilateral	Retired	3	No	7	I
18	Female	81	Infarct	Cerebellum	Left	Retired	0	No	22	I
19	Female	81	Infarct	Internal capsule	Left	Retired	4	Yes	9	I

Abbreviations: C, control group; I, intervention group; NA, not available; NIHSS, National Institute of Health Stroke Scale.

these into code groups, (3) Each code group was sorted into subgroups, and the contents were reduced into a condensate written in first person and illustrated with quotes. Condensates were read by MS, ECA, and BN. Interpretations, informed by the theoretical framework, were discussed with the second author (HDJ), and (4) Each condensate was rewritten as an analytical text in third person and then validated to ensure that the syntheses of the data reflected the original context. All authors reviewed, revised, and discussed the final manuscript. An example of the analysis process is depicted in Table 4. The analysis generated three categories, each with two subgroups (Table 5).

2.6 | Research team and reflexivity

In aiming for transparency, we have adhered to the Standards for Reporting Qualitative Research (SRQR; O'Brien et al., 2014). Reflexivity was maintained through the preparation, analysis, and writing by discussing and challenging our established assumptions. BN, ECA, and MS are physiotherapists, KBA is a neurologist, and HDJ is a philosopher with expertise in enactive theory. The physiotherapy and neurology background provided the group with varied positioned insights (Paulgaard, 1997) that assisted MS, ECA, BN and KBA with creating the interview guide—a process in which a user representative participated. The group's positioned insights, along with HDJ's outsider perspective, facilitated multiple interpretations. None of the authors were personally or professionally acquainted with any of the participants.

2.7 | Ethical considerations

The study was approved by the Regional Committee for Medical Research Ethics North Norway (REK North: 2017/1961). Informed, written consent for participation in the RCT and for the interview study (if selected) was obtained from all participants, and data were anonymized. Consent was verbally confirmed prior to interviews.

3 | RESULTS

3.1 | Explicit or embedded: Diversity of approaches

3.1.1 | Assessment: A tool for the physiotherapist

Descriptions of the initial encounter with the physiotherapist ranged from having a conversation, testing of strength and balance, to no

TABLE 4 Examples of the analysis process

Step 1, preliminary themes	Step 2, examples of meaning units	Step 3, code group, *sub-groups, and condensates (excerpts)*			Step 4, category and analytical text
Trust To be challenged Support Receiving feedback Positivity	*It is important that they take this seriously, that they find it important* *I trusted her a lot, she was good at making me do the exercises, even when I thought I couldn't* *That they show engagement, that's the most important thing. They look after you, you know* *He made these tiny changes and suddenly I could do the same exercise without pain*	Relations and roles	*Trust in professional knowledge* It felt important that he looked after me, that he suggested adjustments when some exercises hurt a bit. It helped straight away, I did the same exercise with no pain. You have to believe in what they are doing, that they are doing the right thing to help you get better and you need to do as you are told. I guess they knew what was right to do, that they have seen me. She came up with lots of things I would never have thought of. She was incredibly skilled at spotting my weaker points	*Engagement, presence, and feedback* The comments from the physiotherapist saying "you did this better than last week" really created the motivation to continue. That she made me feel a certain progress throughout this period, and that she seemed to care. That you're not just there as a thing, but as a person. I Get motivation from being pushed and from their guidance. It means a lot. If he hadn't been there and payed attention I wouldn't have worked so hard. That they support med and give positive feedback. I Was a bit depressed from time to time and the physiotherapist was particularly good at motivating me	Interaction: Supportive and demanding Participants view trust as the most important aspect of their interaction with the physiotherapist. Trust was mainly brought forward in the context of having trust in the physiotherapist's professional opinions and decisions made regarding their treatment. It was also important to feel able to trust that the therapist was honest. Participants valued their physiotherapist professional opinion and wanted to be challenged, pushed and corrected in therapy. Simultaneously they found it important that the physiotherapist was supportive, understanding and someone they could talk to

TABLE 5 Categories and subgroups

Categories	Subgroups
Explicit or embedded: Diversity of approaches	Assessment, a tool for the physiotherapist
	Goal-setting, tacit or spoken
Interventions and perceived bodily changes: Function and fitness	General and individualized
	Meaningful exhaustion
Interaction: Supportive and demanding	Trust and professional knowledge
	Engagement, presence, and feedback

formal assessment. Some assessments were thorough while others were perceived as superficial or partial. Two participants, for example, reported an assessment of only the affected body part, such as a paretic hand. Those participants who did not report a formal assessment, still perceived one integrated into their treatment. They construed the physiotherapist's observations as the basis for the assessment:

> *We talked a little and then I think we did a couple of exercises. I suppose she needed an introduction to figure out what I was able to do and where I stood* (ID17, 75 years old, IG).

Regardless of approach, the participants in both groups trusted the physiotherapists' professional choices and expressed little approval or disapproval. They described these encounters in neutral terms and seemed to acknowledge the initial assessment as being for the physiotherapist, rather than for themselves.

3.1.2 | Goal-setting: Tacit or spoken

Goal-setting also varied within groups. In the rehabilitation units, this process often occurred in a multidisciplinary context where the patients actively voiced their thoughts about goals and priorities.

This was viewed positively, one participant describing it as being heard and the focus of attention. Such explicit processes were not recounted amongst those who had physiotherapy in the municipalities. Sixteen participants reported having reflected upon their personal goals, such as "getting better" or returning to their previous level of function. Interestingly, among the 11 participants who had not received in-patient rehabilitation, 8 had never spoken about goals with their physiotherapist.

> *I had no idea if there were any goals, I guess it was to make me improve my function, she (the physiotherapist) decided on what to do, I would not know why to choose which exercise. I was just happy to get the physiotherapy* (ID18, 81 years old, IG).

When interventions were targeted and tailored to the users' needs, this was interpreted as a tacit, mutual understanding with regards to the aim of therapy. Only one respondent found that the lack of explicit goals reduced their motivation for physiotherapy.

3.2 | Interventions and perceived bodily changes: Function and fitness

3.2.1 | General and individualized

Participants in both groups reported that the physiotherapist chose the content of the sessions, and that balance-, gait-, and stair-training were central elements. Group differences were more distinct in the accounts of content and mode of delivery. The participants in the IG described mainly one-on-one therapy utilizing bodyweight exercises, sensory stimulation supported by hands-on interactions, and verbal explanations as outlined in the intervention guidelines. Several perceived immediate changes during a therapy session, which they found surprising. They frequently demonstrated knowledge about the purpose of exercises (i.e., that the intervention targeted core strength) and largely spoke of improvements in terms of felt bodily changes.

> *We talked about the exercises and which muscles we used. I felt more in contact with my body, that I used the muscles around my pelvis and back. They make me stronger, my balance is better and I have more control over my arm and leg* (ID19, 81 years old, IG).

In the UG, measures were also mostly exercise-based, yet more often performed in a gym utilizing a mix of bodyweight exercises, apparatuses, weights, and endurance-training equipment. Approaches were structured around interval-based training or repetitions and sets. Progress was generally measured through increased resistance or number of repetitions.

> *He said I was weaker in one leg and that we were going to make it as strong as the other. I was to use the leg press-machine. I started doing 45 kg, then 60 kg and now I am doing 65 kg* (ID10, 82 years old, UG).

Positive bodily changes were reported by 15 participants across groups, and were the most important factor in maintaining motivation. Individual tailoring, variations, and gradual progressions in tasks and exercises were appreciated and interpreted as evidence of progress toward their goals.

> *I am in much better shape now than I was before the stroke. It must be the training, I'm sure. I am stronger and it is easier to walk, I hardly use my walker anymore* (ID5, 77 years, IG).

Progress in this context comprised not only regaining bodily control or functioning in ADL, but also gradual improvements in general strength and endurance. One participant felt that the exercises did not suit them since they differed greatly from their previous experience of passive treatments in physiotherapy.

3.3 | Meaningful exhaustion

The majority of participants wanted to be challenged, pushed, and corrected in therapy to bring about progress and a feeling of achievement. High-intensity training generated optimism, as the exertion was interpreted as a sign of normality, or that "the body is working."

> *He always tried to get some momentum into what we were doing. He tried to get across that if you don't push yourself, if you don't try then nothing will happen. He didn't say it but it was there in the way things were done* (ID15, 62 years old, UG).

Repetitive training and exercises that were insufficiently targeted or challenging were depicted as negative features that diminished their commitment.

> *I got bored with it. It was always the same, we did the same tasks every time. It made it easier for me to say bye* (ID12, 39 years old, IG).

Eleven participants reported feeling very tired for one or two hours after physiotherapy, particularly in the early stages. For most, this eased as their endurance improved, which made some feel more positively about physiotherapy.

> *No matter how fatigued I felt that day, once I got to the physiotherapy clinic I just did it. I would not have been able to cope with the music or noise in a normal gym. My physiotherapist made me work really hard for a whole hour and I felt fine* (ID10, 82 years old, UC).

The tiredness following physiotherapy is differentiated from the daily fatigue with which several of the participants struggled. One said that, due to their history, they had not thought it possible to experience such progress, and they were now keen to see how far training could take them.

3.4 | Interaction: Supportive and demanding

3.4.1 | Trust in professional knowledge

Trust was viewed as the most important aspect of the interaction with the physiotherapist. Two main features were highlighted: (1) trust in the physiotherapist's professional opinions and decisions and (2) feeling safe to be personal in the interaction. All participants trusted the physiotherapist's knowledge and abilities.

> *If they had not shown engagement like they did I wouldn't have known what to do. That would have been my biggest problem. I wouldn't have known how to get out of that wheelchair. They worked gradually, every step seemed unachievable initially, and then you manage. I could not have done that alone* (ID14, 71 years old, UG).

Two participants were told by their physiotherapist that their goals were unrealistic. Both initially felt disappointed, but they ultimately appreciated the honesty and respected the professional evaluation.

3.5 | Engagement, presence, and feedback

The participants valued that their physiotherapist showed commitment, exhibited a supportive and understanding attitude, and served as someone they could talk to. One described his physiotherapist as "fun and serious" and found both features important, along with the physiotherapist being "a bit psychologist." The role of the physiotherapist as an engaging motivator who expresses engagement during challenging times was recognized as essential, and their feedback during sessions was emphasized as crucial.

> *You wouldn't put your soul into it like you do when you hear: Awesome! good job! or things like that. Then you know that you are doing your best* (ID2, 75 years old, UG).

The participants valued the physiotherapist's feedback, whether in the form of verbal praise or through verbal and/or tactile cues provided during specific movements or exercises.

> *She held me and pushed me forward at the same time in a way that made me straighten up my upper body. It is like it did something to me, immediately after she finished. It felt like I could walk better* (ID14, 71 years old, UG).

The physiotherapist's presence was deemed important, even when simply checking in on participants at the gym. Many feared that they would not be able to maintain their achievements independently.

4 | DISCUSSION

The participants in this study revealed that interaction with the physiotherapist, which was guided by felt bodily changes, ranged from formal/explicit to tacit/implicit. Experiencing positive bodily changes, along with tailored difficulty and intensity in training, were essential contributors to the development of meaning and motivation, regardless of approach. In the interaction between the patient and the physiotherapist, the latter set the parameters for what to do and how to do it. Trust and engagement were also paramount and multifaceted in this context, involving both interpersonal skills and professional expertise.

4.1 | Embodiment: The missing link

An embodied approach appeared to be more integrated into goal-setting and treatment than into assessment. Participants commonly saw the assessment as being evaluated, rather than playing an active role. It seems that when the body is viewed from a third-person perspective as a biological and biomechanical system, rather than as an embodied self, an opportunity is missed for an interactive approach to assessment—one that could edify both patient and therapist and could clarify how underlying impairments influence movement problems (Normann, 2020). Previous research has shown engagement and sense-making to be facilitated through felt bodily changes (Normann et al., 2013). Our results highlight the need to make the assessment not simply a baseline for the physiotherapist's clinical reasoning, but also a relevant and meaningful learning opportunity for the patient.

In the literature, goal-setting processes are often treated as single activities isolated from other rehabilitation processes (Plant & Tyson, 2018), with many barriers to their implementation (Lloyd et al., 2014). In our material there was a marked difference between how goal-setting was carried out in multidisciplinary in-patient settings and monodisciplinary out-patient settings. In contrast to the current literature advocating SMART[2] goals for such processes (Plant & Tyson, 2018), our results suggest that goal-setting, particularly in the one-on-one setting in practice, is often tacit and implicit—and to a larger extent evaluated/confirmed through felt bodily changes. In the multidisciplinary team setting, explicit goals seemed to have a more overarching, coordinative function. Yet they are still confirmed and evaluated by bodily changes in the day-to-day therapist–patient interaction. Our findings are supported by research suggesting that goal-setting is not separate from the treatment situation, but rather interlinked and integrated—and thus often under-documented (Jung et al., 2017). For the written or verbally set goals to make sense, there is a need for coherence between these and the embodied experiences of the therapy situation.

There were differences between groups in their descriptions of content, their understandings of the purpose behind the exercises, and in their accounts of what constituted progress. Felt bodily change is a key to engagement and sense-making, although expressed in different forms. While the participants in the IG spoke of the progress they made in terms of regaining control of their bodies, those in the UG measured progress more in terms of external, quantitative measures. Regardless of approach, it is vital that progress—the gradual increase in difficulty vis-à-vis the patient's goals—even if not explicit, makes sense, creates engagement, and facilitates meaning-making processes. It seems that there was a stronger emphasis on specificity and on awareness of purpose in the IG. However, focus on strength and endurance training, such as that expressed in the UG, is recommended (Saunders et al., 2020). A combination of approaches, providing both specificity and intensity, as endorsed by Pollock et al. (2014), should also be feasible. The improvements in strength and endurance were particularly significant during plateaus in recovery of activity of daily living (ADL). Such improvements served as a confirmative link between effort and gains, and as such made the endeavor and exhaustion meaningful. It is noteworthy that the exhaustion following exercise was well tolerated and essentially perceived differently than that associated with fatigue, which more often was related to noisy environments or social settings with which several participants struggled in their daily lives. Our findings point to how embodiment and the co-construction of meaning, occurring through verbal and nonverbal actions and physical interactions, are integrated in physiotherapy practice.

4.2 | Interaction

Interactions, such as that between a patient and a physiotherapist, are always shaped by self-regulated norms and established power-relations. The participants make sense of each other, their actions, and their surroundings together through participatory sense-making (Fuchs & De Jaegher, 2009). Trust is central to this process. The expectations of how an interaction with a physiotherapist would proceed are, in enactive terms, part of a participation genre (Di Paolo et al., 2018). The patient's acceptance of the physiotherapist as the decision-maker in this interaction, is also part of such a genre. The fact that a physiotherapist possesses the adequate professional knowledge and will make optimal decisions on the treatment is implicitly assumed and functions as a premise for the interaction (Roenn-Smidt et al., 2020). The physiotherapist's role is complex, as they are also expected to provide emotional support, as well as to motivate and to push the patient with regards to intensity in training. When fulfilling these expectations, the physiotherapist is the regulator of the interaction. We found that the patient's expectations for physiotherapy are mainly connected to the physiotherapist's traits and not to the specific content of therapy. Our results are in line with those by Sheppard et al. (2010), who found that such traits are often referred to as the physiotherapist's personal characteristics, yet in practice are impossible to distinguish from their professional manner, since motivation and communication skills are part of the professional role. The patient's own role in the interaction is to exert the required effort. Although patients seemingly “do as they're told” in physiotherapy, they are autonomous participants and active agents; they possess the capacity to regulate the interaction through their efforts. If the central criterion of experiencing positive bodily changes is not met, the patient may become the regulator of the encounter by reducing their engagement and efforts or by withdrawing from therapy entirely.

4.3 | Limitations

This study was conducted in two regions in Norway, limiting the findings to the Scandinavian health care system. The main features of physiotherapy treatment, however, are shared internationally, and applying concepts from enactive theory serve as a theoretical generalization (Malterud, 2015). We sampled participants strategically, aiming for a broad sample, but cannot rule out the possibility that excluded participants may have been able to add valuable contributions. Furthermore, the criteria for participation in the RCT influenced the sample, as these excluded those with more severe disabilities. Some interviews were delayed, which might have interfered with the participant's ability to remember events and perhaps introduced recall bias. Our impression, however, was that most participants recalled the events clearly.

5 | CONCLUSION

This study highlights how embodiment, along with the co-construction of meaning that occurs through verbal and nonverbal actions and physical interactions, are integral to physiotherapy practice. Experiencing bodily changes and exertion from post-stroke training can facilitate sense-making, galvanize commitment, and inspire a positive attitude toward physiotherapy. Trust is an essential part of the interaction between patient and physiotherapist. Patients find that a physiotherapist's ability to apply professional knowledge, to motivate their patients, and to provide emotional support are fundamental aspects of their role.

5.1 | Implications for physiotherapy practice

- Assessments must be made meaningful and instructive for patients—a process that is facilitated by recognizing the body as the locus of experience and expression. Simultaneously as being a biological organism.
- Improvements in general fitness contribute significantly to maintaining motivation during plateaus in ADL-recovery.

ACKNOWLEDGMENTS

We would like to thank the individuals who participated in this study, Nordland and Nord-Trøndelag Hospital Trust for their support and for contributing to data collection in this research project, the participating municipalities and the user representative. The study was funded by the Northern Norway Regional Health Authority.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Britt Normann, Marianne Sivertsen, Karl Bjørnar Alstadhaug, and Ellen Christin Arntzen contributed to the design of the study. Marianne Sivertsen conducted the interviews. Marianne Sivertsen, Britt Normann, and Ellen Christin Arntzen contributed to the analysis of the data. Marianne Sivertsen drafted the manuscript. All authors contributed to the interpretation of data, critically revised the manuscript and gave final approval.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Marianne Sivertsen https://orcid.org/0000-0003-0895-1081
Hanne De Jaegher https://orcid.org/0000-0001-7273-6410

ENDNOTES

[1] I-CoreDIST: Individualized Core activation combined with DISTal functional movement. I = individualized, Core = trunk, D = dual task, I = intensive, S = specific, stability, somatosensory stimulation, and T = teaching, training.

[2] SMART = Specific, Measurable, Achievable, Realistic, Timely.

REFERENCES

Arntzen, E. C., Oberg, G. K., Gallagher, S., & Normann, B. (2019). Group-based, individualized exercises can provide perceived bodily changes and strengthen aspects of self in individuals with MS: A qualitative interview study. *Physiotherapy Theory and Practice*, *37*, 1–16.

Arntzen, E. C., Straume, B. K., Odeh, F., Feys, P., Zanaboni, P., & Normann, B. (2019). Group-based individualized comprehensive core stability intervention improves balance in persons with multiple sclerosis: A randomized controlled trial. *Physical Therapy*, *99*(8), 1027–1038. https://doi.org/10.1093/ptj/pzz017

Bernhardt, J., Godecke, E., Johnson, L., & Langhorne, P. (2017). Early rehabilitation after stroke. *Current Opinion in Neurology*, *30*(1), 48–54.

Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the craft of qualitative research interviewing* (3rd ed.). Sage.

Busetto, L., Stang, C., Hoffmann, J., Amiri, H., Seker, F., Purrucker, J., & Stroke Consortium, R.-N. (2020). Patient-centredness in acute stroke care – A qualitative study from the perspectives of patients, relatives and staff. *European Journal of Neurology*. https://doi.org/10.1111/ene.14283

Cresswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design. Choosing among five approaches*. (4th ed.). Sage Publications Ltd.

Danzl, M. M., Etter, N. M., Andreatta, R. D., & Kitzman, P. H. (2012). Facilitating neurorehabilitation through principles of engagement. *Journal Of Allied Health*, *41*(1), 35.

Di Paolo, E. A., Cuffari, E. C., & De Jaegher, H. (2018). *Linguistic bodies: The continuity between life and language*. The MIT Press.

Frykberg, G. E., & Vasa, R. (2015). Neuroplasticity in action post-stroke: Challenges for physiotherapists. *European Journal of Physiotherapy*, *17*, 56–65.

Fuchs, T., & De Jaegher, H. (2009). Enactive intersubjectivity: Participatory sense-making and mutual incorporation. *Phenomenology and the Cognitive Sciences*, *8*, 465–486.

Galvin, R., Cusack, T., & Stokes, E. (2009). Physiotherapy after stroke in Ireland: A qualitative insight into the patients' and physiotherapists' experience. *International Journal of Rehabilitation Research*, *32*(3), 238–244. https://doi.org/10.1097/MRR.0b013e32832b083c

Jansson, A.-S. B., & Carlsson, G. (2021). Physical activity on prescription at the time of stroke or transient ischemic attack diagnosis - From a patient perspective. *Disability & Rehabilitation*, *43*(8), 1121–1128. https://doi.org/10.1080/09638288.2019.1650296

Jung, K. S., In, T. S., & Cho, H. Y. (2017). Effects of sit-to-stand training combined with transcutaneous electrical stimulation on spasticity, muscle strength and balance ability in patients with stroke: A randomized controlled study. *Gait & Posture*, *54*, 183–187. https://doi.org/10.1016/j.gaitpost.2017.03.007

Kelly, K., Brander, F., Strawson, A., Ward, N., & Hayward, K. (2020). Pushing the limits of recovery in chronic stroke survivors: A descriptive qualitative study of users perceptions of the queen square upper limb neurorehabilitation programme. *BMJ Open*, *10*(10), e036481.

Kjellstrom, T., Norrving, B., & Shatchkute, A. (2007). Helsingborg Declaration 2006 on European stroke strategies. *Cerebrovascular Diseases*, *23*(2–3), 231–241. https://doi.org/10.1159/000097646

Levin, M. F., & Demers, M. (2020). Motor learning in neurological rehabilitation. *Disability and Rehabiltation*, 1–9. https://doi.org/10.1080/09638288.2020.1752317

Lloyd, A., Bannigan, K., Sugavanam, T., & Freeman, J. (2018). Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation: A systematic review of qualitative evidence. *JBI Database of Systematic Reviews & Implementation Reports*, *16*(6), 1418–1453. https://doi.org/10.11124/JBISRIR-2017-003499

Lloyd, A., Roberts, A. R., & Freeman, J. A. (2014). 'Finding a balance' in involving patients in goal setting early after stroke: A physiotherapy perspective. *Physiotherapy Research International*, *19*(3), 147–157. https://doi.org/10.1002/pri.1575

MacDonald, G. A., Kayes, N. M., & Bright, F. (2013). Barriers and facilitators to engagement in rehabilitation for people with stroke: A review of the literature. *New Zealand Journal of Physiotherapy*, *41*(3), 112–121.

Malterud. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, *40*(8), 795–805. https://doi.org/10.1177/1403494812465030

Malterud, K. (2015). Theory and interpretation in qualitative studies from general practice: Why and how? *Scandinavian Journal of Public Health*, *44*(2), 120–129. https://doi.org/10.1177/1403494815621181

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Merleau-Ponty, M. (2008). *Phenomenology of perception*. Routhledge Classics.

Newell, K. M., & Verhoeven, F. M. (2017). Movement rehabilitation: Are the principles of re-learning in the recovery of function the same as those of original learning? *Disability & Rehabilitation*, *39*(2), 121–126. https://doi.org/10.3109/09638288.2016.1170895

Normann, B. (2020). Facilitation of movement: New perspectives provide expanded insights to guide clinical practice. *Physiotherapy Theory and Practice*, *36*(7), 769–778. https://doi.org/10.1080/09593985.2018.1493165

Normann, B., Arntzen, E. C., & Sivertsen, M. (2019). Comprehensive core stability intervention and coordination of care in acute and subacute stroke rehabilitation-a pilot study. *European Journal of Physiotherapy*, *21*(4), 187–196. https://doi.org/10.1080/21679169.2018.1508497

Normann, B., Sørgaard, K. W., Salvesen, R., & Moe, S. (2013). Contextualized perceptions of movement as a source of expanded insight: People with multiple sclerosis' experience with physiotherapy. *Physiotherapy Theory and Practice*, *29*(1), 19–30. https://doi.org/10.3109/09593985.2012.698717

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/acm.0000000000000388

Pak, P., Jawed, H., Tirone, C., Lamb, B., Cott, C., Brunton, K., & Inness, E. L. (2015). Incorporating research technology into the clinical assessment of balance and mobility: Perspectives of physiotherapists and people with stroke. *Physiotherapy Canada [Physiotherapie Canada]*, *67*(1), 1–8. https://doi.org/10.3138/ptc.2013-63

Paulgaard, G. (1997). Feltarbeid i egen Kultur: Innenfra, utefra eller begge deler? Fieldwork in their own culture: From within or both? In E. Fossåskåret, O. L.Fuglestad, & T. H.Aase (Eds.), *Metodisk feltarbeid. Produksjon og tolkning av kvalitative data. [Methodical fieldwork. Production and interpretation of qualitative data]* (pp. 70–93). Universitetsforl.

Peiris, C. L., Taylor, N. F., & Shields, N. (2012). Patients value patient-therapist interactions more than the amount or content of therapy during inpatient rehabilitation: A qualitative study. *Journal of Physiotherapy*, *58*(4), 261–268. https://doi.org/10.1016/s1836-9553(12)70128-5

Plant, S., & Tyson, S. F. (2018). A multicentre study of how goal-setting is practised during inpatient stroke rehabilitation. *Clinical Rehabilitation*, *32*(2), 263–272. https://doi.org/10.1177/0269215517719485

Pollock, A., Baer, G., Campbell, P., Choo, P. L., Forster, A., Morris, J., & Langhorne, P. (2014). Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database of Systematic Reviews*, *2014*(4), CD001920. https://doi.org/10.1002/14651858.CD001920.pub3

Pound, P., Bury, M., Gompertz, P., & Ebrahim, S. (1994). Views of survivors of stroke on benefits of physiotherapy. *International Journal for Quality in Health Care*, *3*(2), 69–74. https://doi.org/10.1136/qshc.3.2.69

Roenn-Smidt, H., Larsen, K., & Pallesen, H. (2020). The practices of body in rehabilitation after stroke: A qualitative study of how physiotherapy affects identity reconstruction. *European Journal of Physiotherapy*, 1–9. https://doi.org/10.1080/21679169.2020.1730440

Saunders, D. H., Sanderson, M., Hayes, S., Johnson, L., Kramer, S., Carter, D. D., & Mead, G. E. (2020). Physical fitness training for stroke patients. *Cochrane Database of Systematic Reviews*, *3*(3), CD003316. https://doi.org/10.1002/14651858.CD003316.pub7

Sheppard, L. A., Anaf, S., & Gordon, J. (2010). Patient satisfaction with physiotherapy in the emergency department. *International Emergency Nursing*, *18*(4), 196–202. https://doi.org/10.1016/j.ienj.2009.11.008

Thompson, E. (2007). *Mind in life: Biology, phenomenology, and the sciences of mind*. The Belknap Press of Harvard University Press.

Yun, D., & Choi, J. (2019). Person-centered rehabilitation care and outcomes: A systematic literature review. *International Journal of Nursing Studies*, *93*, 74–83. https://doi.org/10.1016/j.ijnurstu.2019.02.012

How to cite this article: Sivertsen, M., De Jaegher, H., Arntzen, E. C., Alstadhaug, K. B., & Normann, B. (2022). Embodiment, tailoring, and trust are important for co-construction of meaning in physiotherapy after stroke: A qualitative study. *Physiotherapy Research International*, e1948. https://doi.org/10.1002/pri.1948

Appendix 1-7

Appendix 1

Example of clinical reasoning charts

Goals of performance in sitting and assessment of deviations from these

GOALS or movement competencies	Can?	How is the movement performed? Stability/ instability/BOS?	What specific hands-on interactions and adaptations improves performance?	Problem?
1)To be able to sit in a symmetrical position with even weightbearing, good contact with the BOS (buttocks and feet), trunk upright, elongated neck, arms by the sides and the hands in contact with the tights/BOS				
2) While keeping this starting position, be able to activate core musculature to for example achieve contact with a therapy ball				
3) While keeping this starting position with an active core, be able to: move eyes, move head, lift the least affected arm, lift the most affected arm, lift both arms (as in supine)				
Transfer weight to least affected side, cross one leg over the other.				
Transfer weight to most affected side, cross one leg over the other				

Continued			
«Pelvic Walk», alternate between pushing right and left knee forward			
Reach to touch the floor on least affected side.			
Reach to touch the floor on most affected side			
Reach up/back/forward with least affected arm			
Reach up/back/forward with most affected arm			
Summary of considerations of reasons for deviations from optimal performance; issues, resources and main problem			
Potential exercises to address the problem?			

Some common aspects to consider: Pelvic alignment and relation to the BOS? Trunk, symmetry/asymmetry of weightbearing? Postural sway? Shape of the thorax? Upright/flexed trunk? Position of the head? If flexor dominated: is the patient actively pulling down or sinking? Pattern of shoulder movements? Alignment of the shoulder? Subluxation? Influence on postural activity from the shoulder/head? Is it easier for the patient to recruit postural activity (length in upper trunk), core activation and /or lateral weight transfer if you facilitate upright position by mobilization/realignment of the neck/head? Provide support (elevated to 90 degrees) to the upper limbs, and/or elevation of the less affected limb? If you realign the pelvis (avoid retraction of affected side) – does this influence postural activity? Weight transfer. If you mobilise the hip/pelvis in back leaned sitting – is it then easier to adapt to BOS, symmetry? Weight transfer? Influence of the hip/pelvis on core activation/postural control etc.

Appendix 2

Interview guide

Interview guide

Sequence	**Theme**	**Opening question** - **Possible questions and probes**
Opening	Aim and plan for the interview,	Plan for the interview Aim, explanation of why we are conducting interviews, the type of knowledge they will generate. That knowledge of both positive and negative experiences may contribute in the development of services. Disclosure of interviewers' role as a researcher and physiotherapist (not involved in the treatment of any participants in this study); that in order to improve clinical practice we need to know both what is perceived as meaningful and what is not.
	The acute situation	Can you tell me about the day you had your stroke? Is there anything you remember particularly well? - What changed in your body - What did you feel, what did you think? - Were you with someone? How did they react?
		Is there anything you remember especially well from the first day in hospital? - Positive, negative experiences, why was this important to you?
	Participation in daily activities and training in hospital	Can you describe a normal day in the stroke unit? - Can you tell me about your first memory from the stroke unit? - Can you describe the atmosphere? - Did you need help at all? Can you describe the help you got? How did you feel about it? - Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you? - How do you feel about the contents of a usual day in the stroke unit/rehabilitation unit? What was particularly good/not great? What would you improve?
		What are your thoughts about the care you received and how it was tailored to your needs?
		Can you tell me about the rehabilitation you received in the stroke unit at the hospital? - Physiotherapy, Occupational therapy, Speech therapy, other? - Can you describe your first session with the physiotherapist? What did you do? What did you learn from that first meeting? How were plans made? - What did you do in the physiotherapy sessions? (what, how, where). Is there anything you remember particularly well? - What was most important to you in rehabilitation (body function, activity, participation levels)? Why was this particularly important? Was there anything that you did

		- not find useful? What was that? What made you feel that way about it? - In what way were what you did in rehabilitation useful with regards to your difficulties. - How were plans for the sessions made
	Transfer from hospital to rehabilitation unit or home Transfer from rehabilitation unit to home	Can you tell me about the day you were discharged from the hospital/rehabilitation unit to the rehabilitation unit or home? - What were your expectations? - When did you learn about the discharge? - What were your feelings about being discharged? - What role did you have in planning when the discharge was going to happen? - Was anyone else involved in this decision - Were any preparations done? What were they and who was involved? - How did you feel about being discharged? (ready/prepared) - Can you tell me about that day, from before leaving the hospital? What was your expectations, feelings, thoughts? - What is the first thing you remember from coming to the rehabilitation unit/home? (good, challenging)
	Daily activities at home	Can you tell me about a normal day at home? - Describe your routines, need for help and access to help if needed, thoughts and reflections around this. - What kind of therapy/training sessions do you have on a regular basis? How do you get to those? How do you feel about these? - Do you exercise/are you active outside of your regular therapy/training sessions? - What else do you do in a normal day?
	In-patient/out-patient rehabilitation	What is the first thing you remember from the rehabilitation unit? Can you describe a normal day in the rehabilitation unit? - Can you describe the atmosphere? - Did you need help at all? Can you describe the help you got? How did you feel about it? - Can you tell me about the daily activities on the ward? What are your thoughts about these? Is there anything you think should have been done differently? What was important to you? How do you feel about the contents of a usual day in the rehabilitation unit? What was particularly good/not great? Why was this important to you? What would you have wanted done differently? Goal setting What was your main goal for rehabilitation? - How were goals set?

		- What was your role in setting, working towards and evaluating goals - Did the goals set reflect your needs? - Can you describe a situation where goals were brought up? When was it brought up, did you express your opinions? Can you tell me about the rehabilitation you received in the rehabilitation unit and/or at home? - Physiotherapy, Occupational therapy, Speech therapy, other` - Can you describe your first session with the physiotherapist? What did you do? What did you learn from that first meeting? How were plans made? - What did you do in the physiotherapy sessions? (what, how, where). Is there anything you remember particularly well? - What was most important to you in rehabilitation (body function, activity, participation levels)? Why was this particularly important? Was there anything that you did not find useful? What was that? What made you feel that way about it? - In what way were what you did in rehabilitation useful with regards to your difficulties. - How were plans for the sessions made
Closure	Rehabilitation course	Did we leave out something that was important to you? Would you like to add something? If you were able to change something about your rehabilitation course, what would that be?
	Interview	Summary How did you find participating in this interview?

Appendix 3

Approval from the Regional Committee for Medical and Health Research Ethics in Norway (in Norwegian)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord	May Britt Rossvoll	77620757	30.10.2017	2017/1961/REK nord
			Deres dato:	Deres referanse:
			19.09.2017	

Vår referanse må oppgis ved alle henvendelser

Britt Normann
Institutt for helse og omsorgsfag

2017/1961 Rehabilitering og samhandling i sykehus og kommune i tidlig fase etter hjerneslag

Forskningsansvarlig: Nordlandssykehuset HF
Prosjektleder: Britt Normann

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 12.10.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektomtale

Denne studien vil gi kunnskap om effekt av en nyutviklet fysioterapi- og tverrfaglig intervensjon for å gjenvinne bevegelseskontroll i daglige aktiviteter etter et hjerneslag og innsikt i hvordan brukerne erfarer rehabilitering etter akutt hjerneslag. Del I av studien skal undersøke om denne nye tilnærmingen, har effekt på gange, balanse, og fysisk aktivitet sammenlignet med standard oppfølging. Kliniske Skype-møter i forbindelse med pasientoverflytting inngår for å styrke kontinuitet i fysioterapitjenesten. Utvalget består av 94 deltakere hvor 47 får den nye treningsformen på tvers av helsetjenestenivåene og 47 får standard oppfølging. Alle testes med ulike måleredskaper etter innleggelse i sykehus og etter 12 uker. Del II av studien skal undersøke hva slags erfaringer og refleksjoner deltakerne har i forhold til innhold, medvirkning og samhandling i rehabiliteringsforløpet. Dette undersøkes ved hjelp av kvalitative forskningsintervju med 14-16 deltakere i hver gruppe.

Vurdering

Deltakere/rekruttering

Utvalget består av 94 deltakere hvor 47 får den nye treningsformen på tvers av helsetjenestenivåene og 47 får standard oppfølging.

Det er opplyst at pasienter rekrutteres fra slagenheten ved Nordlandssykehuset i Bodø, der de er innlagt med akutt hjerneslag. Intervensjonsgruppen er de som er hjemmehørende i Bodø og kontrollgruppen er pasienter som har Nordlandssykehuset som sitt lokale sykehus, men som er hjemmehørende i de øvrige nevnte kommuner.

Det beskrives i søknaden at innleggende lege screener om pasientene fyller kriterier for inklusjon, og sender så melding til prosjektmedarbeider som gir pasienten/pårørende informasjon om studien, samt innhenter samtykke. For ikke å bryte taushetsplikten må innleggende lege ha samtykke fra pasienten eller pårørende dersom pasienten ikke er samtykkekompetent, for å videreformidle informasjon om pasienten til prosjektmedarbeider.

Et eventuelt samtykke til deltakelse må kunne leveres/sendes inn på eget initiativ til prosjektet.

Personer uten eller med redusert samtykkekompetanse

Forskning som inkluderer personer uten eller med redusert samtykkekompetanse kan bare finne sted dersom eventuell risiko eller ulempe for personen er ubetydelig, personen selv ikke motsetter seg det, og det er grunn til å anta at resultatene av forskningen kan være til nytte for den aktuelle personen eller for andre personer med samme aldersspesifikke lidelse, sykdom skade eller tilstand. Det må heller ikke være grunn til å tro at personen ville motsatt seg deltakelse i forskningsprosjektet hvis vedkommende hadde hatt samtykkekompetanse. Det er også et krav at tilsvarende forskning ikke kan gjennomføres på personer med samtykkekompetanse, jf. helseforskningslovens § 18.

Komiteen har vurdert disse krav som oppfylt.

Data

Data skal hentes fra pasientjournal, gjennom kliniske tester og gjennom intervju.

Nye kliniske data ved baseline og etter 12 uker.

Data behandles avidentifisert.

Metode

Alle deltakere skal testes med ulike måleredskaper etter innleggelse i sykehus og etter 12 uker. Del II av studien gjøres med kvalitative forskningsintervju med 14-16 deltakere i hver gruppe.

Studien er en klinisk randomisert studie, hvor utvalget til intervju skal gjøres gjennom strategiske valg. I tekst i informasjon-/samtykkeskjema opplyses det at kontrollgruppen får samme tilbud som intervensjonsgruppen mens pasientene ligger på Nordlandssykehuset. Når de blir utskrevet vil kontrollgruppen bli fulgt opp av sin hjemkommune med de tiltak som er tilgjengelig der.

Komiteen vurderer at randomiseringen kan medføre bias pga. skjevhet i utvalget. Det antas at de to gruppene kan være forskjellige mht. utdanning og ressurser. Komiteen har likevel lagt prosjektleders begrunnelse for randomiseringen til grunn i vurderingen.

Informasjon-/samtykkeskjema

Overskriften på informasjon-/samtykkeskjema er ikke overensstemmende med overskrift/tittel på prosjektsøknad. På skrivet til kontrollgruppen er det i tillegg påført «en pilotstudie». Dette må det rettes opp i. Nye korrigerte informasjon-/samtykkeskriv må sendes inn.

Samarbeid med utlandet

Dette beskrives som hjelp til måling av postural kontroll, EMG og kraftplattform med diskusjoner i forberedelsesfasen, analyse av data (avidentifisert) og publikasjon av resultater. Det legges til grunn at vedkommende bidrar til dette der studien gjennomføres, ved Nordlandssykehuset, eller at data overføres avidentifisert.

Bidrag i analyse av datamaterialet, og det legges til grunn at dette gjelder avidentifisert data.

Vedtak

Med hjemmel i helseforskningsloven §§ 2 og10 godkjennes prosjektet.

Før prosjektet kan igangsettes må det sendes inn revidert informasjonsskriv i tråd med komiteens merknader. Skrivet sendes som vedlegg i e-post til post@helseforskning.etikkom.no

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest 27.12.2021, 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
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar 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

#KOMITELEDER_NAVN#
#KOMITELEDER_AKADEMISK_GRAD#
#KOMITELEDER_STILLING#

May Britt Rossvoll
sekretariatsleder

Kopi til:paul.martin.strand@nordlandssykehuset.no

Appendix 4

Approval of changes to the project from the Regional Committee for Medical and Health Research in Norway (in Norwegian)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK nord	Lill Martinsen	77620753	19.10.2018	2017/1961/REK nord
			Deres dato:	**Deres referanse:**
			13.09.2018	

Vår referanse må oppgis ved alle henvendelser

Britt Normann
Institutt for helse og omsorgsfag

2017/1961 Rehabilitering og samhandling i sykehus og kommune i tidlig fase etter hjerneslag

Forskningsansvarlig: Nordlandssykehuset HF
Prosjektleder: Britt Normann

Vi viser til søknad om prosjektendring datert 24.8.2018, samt tilbakemelding av 13.09.2018 på vår e-post av 4.9.2018, for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK nord på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Oppdatert protokoll av 30.8.18. og oppdatert informasjons-/samtykkeskjema versjon av 24.8.18, er vedlagt..

Det framgår at de omsøkte endringer gjelder endring i inklusjonskriteriene, fra 80 år til 85 år, samt nye prosjektmedarbeidere, endring av prosjektperiode, økning i antall deltakere, og endring av prosjektets design. Det søkes også om endring av rekrutteringsmetode fra inklusjon når pasientene er innlagt på slagenheten, til at pasienten blir rekruttert ved utskriving fra sykehuset.

REK minner om at svar på forespørsel om deltakelse ikke bør innhentes i en konsultasjons-/behandlingssituasjon og det må ikke avkreves et aktivt nei-svar hvis man ikke vil delta. Det må gis betenkningstid slik at de forespurte kan rådføre seg med andre. Et eventuelt samtykke til deltakelse må kunne leveres/sendes inn på eget initiativ. Det forutsettes at disse prinsippene blir ivaretatt i prosjektet.

Etter fullmakt er det fattet slikt

Vedtak

Med hjemmel i helseforskningsloven § 11 godkjennes prosjektendringene.

Endringen godkjennes under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknaden, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter. For øvrig gjelder de vilkår som er satt i forbindelse med tidligere godkjenning av prosjektet.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar 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

Lill Martinsen
rådgiver

Kopi til: *paul.martin.strand@nordlandssykehuset.no*

Appendix 5

Approval from the data protection officer at Nordland Hospital Trust (in Norwegian)

NORDLANDSSYKEHUSET
NORDLÁNDA SKIPPIJVIESSO

Til:
Britt Normann
Hode- og bevegelsesklinikken
Nordlandssykehuset HF

Tony Bakkejord
Kirurgisk klinikk
Nordlandssykehuset HF

Tove Kaspersen Beyer
Hode- og bevegelsesklinikken
Nordlandssykehuset HF

Saksnr i Elements .:	Saksbeh.:	Dato:
2019/6490	Julie Rydland Antonsen	04.09.19

Vedrørende personvernkonsekvensvurdering for forskningsprosjekt

Prosjektnummer: 34-19

Prosjekttittel: Innovative physiotherapy in stroke rehab

Prosjektperiode: 01.04.19-31.03.24

Prosjektansvarlig virksomhet: Nordlandssykehuset HF

1. Vurdering fra personvernombudet

Rettslig grunnlag

I prosjektet behandles både alminnelige personopplysninger og særlige kategorier av personopplysninger (helseopplysninger). Behandling av personopplysninger i prosjektet har hjemmel i følgende behandlingsgrunnlag:

- Personvernforordningen artikkel 6 første ledd bokstav e) og artikkel 9 annet ledd bokstav j)
- Spesialisthelsetjenesteloven § 3-8 3., jf. helseforskningsloven § 35

Personvernprinsipper

Personvernombudets vurdering er at den planlagte behandlingen av personopplysninger vil overholde prinsippene i personvernforordningen.

Håndtering av personopplysningene

Personopplysningene i prosjektet skal håndteres på sikker måte. Det anbefales at det opprettes område for sikker lagring på Nordlandssykehusets server, og at alle personopplysninger i prosjektet lagres på dette filområdet. Seksjon for forskning kan bistå på dette punkt. Ta kontakt på forskning@nordlandssykehuset.no.

Personvernombudets anbefaling

Personvernombudet gir sin anbefaling til gjennomføring av prosjektet, forutsatt at følgende punkter følges:

- Alle endringer i prosjektet må meldes til personvernombudet.
- Det skal ikke samles inn og behandles flere personopplysninger enn det som er nødvendig for å oppfylle formålet med kvalitetsprosjektet.
- Alle personopplysninger skal slettes eller anonymiseres ved prosjektets avslutning.
- Det skal gis tilbakemelding til personvernombudet når personopplysningene er slettet.

Personvernombudets vurdering er at behandlingen av personopplysningene i prosjektet vil være i samsvar med personvernlovgivningen, forutsatt at behandlingen gjennomføres i tråd med opplysningene i meldeskjemaet. Det presiseres at det er prosjektleders ansvar å påse at prosjektet følger gjeldende lovkrav.

Med vennlig hilsen

Julie Rydland Antonsen
Personvernombud

2. Avgjørelse fra ledelsen

Prosjektet godkjennes under forutsetning at anbefaling fra personvernombud følges.

Med vennlig hilsen

Alisa Larsen
Informasjonssikkerhetsansvarlig

Appendix 6

Approval from the data protection officer at Nord-Trøndelag Hospital Trust (in Norwegian)

HELSE NORD-TRØNDELAG
Postboks 333
N-7601 LEVANGER
E-post: postmottak@hnt.no
Telefon: 74 09 80 00
Org.nr: 983 974 791
www.hnt.no

Professor Britt Normann
Nordlandssykehuset HF
Gidsken Jakobsens vei 32

8008 Bodø

Vår ref.:	Deres ref.:	Dato:
2020/2503 - 24434/2020		28.08.2020

Svar på søknad om godkjenning av forskningsprosjekt

Prosjekt:
Innovative physiotherapy in stroke rehabilitation during the subacute stage - a prospective randomized single blinded controlled trial and a qualitative study

Prosjektleder:
Britt Normann, professor, Nordlandssykehuset HF og Nord universitet (hovedveileder)

Forskningsansvarlig:
Nordlandssykehuset HF

Dataansvarlig/Behandlingsansvarlig:
Nordlandssykehuset HF v/administrerende direktør Paul Martin Strand

Forskningsgruppe lokalt/regionalt:
Karl Bjørnar Alstadhaug, overlege, professor, Nordlandssykehuset HF, UiT Norges Arktiske Universitet, Institutt for klinisk medisin (biveileder)
Ellen Christin Arntzen, ph.d., Nordlandssykehuset HF (biveileder)
Marianne Sivertsen (ph.d.-student)
Tove Vannes Sundby, fysioterapeut, Helse Nord-Trøndelag HF (HNT) (prosjektmedarbeider)

Prosjektets formål og bakgrunn:
Mange som overlever hjerneslag får varige funksjonsnedsettelser. Det er enighet om at fysioterapi med høyt volum og høy intensitet gir bedre effekt, men det er manglende kunnskap om hva som skal inngå i denne treningen. Hensikten med studien er (1) å undersøke om en ny fysioterapitilnærming (I-CoreDIST) gir bedre effekt på balanse, gange, fysisk aktivitet og livskvalitet i subakutt fase etter et hjerneslag sammenliknet med standard oppfølging og (2) hva erfarer pasientene som meningsfylte sider ved innhold og koordinering i rehabilitering, inklusive fysioterapi.

Datamateriale og datahåndtering:
Prosjektet omhandler fysioterapibehandling etter hjerneslag på tvers av helsetjenestenivå og omfatter Nordlandssykehuset Bodø, Sykehuset Levanger, rehabiliteringsavdelinger i deres nedslagsfelt og omkringliggende kommuner.

Utvalget består av 94 deltakere hvor 47 får den nye treningsformen på tvers av helsetjenestenivåene og 47 får standard oppfølging. Alle testes med ulike måleredskaper etter innleggelse i sykehus og etter 12 uker. Del I av studien skal undersøke om denne nye tilnærmingen har effekt på gange, balanse, og fysisk aktivitet sammenlignet med standard oppfølging. Kliniske Skype-møter i forbindelse med pasientoverflytting inngår for å styrke kontinuitet i fysioterapitjenesten.

Del II av studien skal undersøke hva slags erfaringer og refleksjoner deltakerne har i forhold til innhold, medvirkning og samhandling i rehabiliteringsforløpet. Dette undersøkes ved hjelp av kvalitative forskningsintervju med 14-16 deltakere i hver gruppe.

Aktuelle deltakere inkluderes fra slagenhet og baseline testing samt randomisering gjøres før utreise. Følgende opplysninger vil bli hentet fra journal: alder, kjønn, tidligere sykdommer, type hjerneslag, lokalisering av hjerneslaget og hvilke utfall pasienten har fått som følge av hjerneslaget. Intervensjonen følger pasienten gjennom forløpet i 12 uker og re-test gjøres i forbindelse med oppfølging ved slagpoliklinikk. Det vil bli gjennomført kliniske tester som samler informasjon om forflytningsevne, balanse og gangfunksjon ved baseline og etter 12 uker. Intervensjonen består av to deler. En fysioterapidel og en tverrfaglig del nærmere beskrevet i prosjektplanen. Fysioterapiintervensjon: etter inklusjon vil fysioterapeut utføre en undersøkelse med fokus på nevrologiske utfall og funksjonsundersøkelse med bevegelsesanalyse som er basis for et individualisert behandlingsforløp.

Avidentifiserte data registreres i testhefter som oppbevares innelåst og overføres til elektronisk database. Elektronisk testdatabase er opprettet i RedCap (http://redcap.helsenord.no). Data lagres på sikker server for lagring av forskningsdata ved Nordlandssykehuset HF. Koblingsnøkkel oppbevares i låst skap, ph.d-kandidat og to personer som foretar inklusjon og testing har tilgang til nøkkel.

Etikk og personvern:
Det innhentes samtykke fra alle deltakere, studien er godkjent av REK nord (2017/1961).

Kostnader/finansiering:
Prosjektet er finansiert av Helse Nord

Prosjektperiode:
01.04.2019.31.03.2022

Publikasjoner:
Ph.d-avhandling med følgende tre publikasjoner:
1. Effects of I-CoreDIST compared to dose-matched standard care on balance in the subacute rehabilitation stage after stroke
2. Effects of I-Core DIST compared to dose-matched standard care on walking, ADL and level of physical activity in the subacute rehabilitation stage after a stroke
3. Experiences of meaning in content and coordination of rehabilitation and physiotherapy in the sub-acute stage following a stroke

Vurdering:

Forskningsansvarlig instans i HNT (DAC) har vurdert søknaden i henhold til personvernforordningen, relevant særlovgivning og HNTs egne retningslinjer/strategier for bruk av pasientdata til forskningsformål.
DAC behandlet søknaden *Innovative physiotherapy in stroke rehabilitation during the subacute stage - a prospective randomized single blinded controlled trial and a qualitative study* den 24. august 2020. Søknaden gjelder rekruttering av slagpasienter ved slagenhet for å undersøke nytten av en ny fysioterapibehandling.

Behandlingsgrunnlag:
Etter ny personopplysningslov har behandlingsansvarlig og prosjektleder et selvstendig ansvar for å sikre at behandlingen av personopplysninger har et lovlig grunnlag. Behandlingsansvarlig institusjon (Nordlandssykehuset HF) viser til behandlingsgrunnlag etter personvernforordningens artikkel 6 nr. 1 bokstav e), og unntak fra forbudet mot behandling av særlige kategorier personopplysninger i artikkel 9 nr. 2 bokstav j). Behandlingen har nasjonalt rettslig grunnlag etter helseforskningsloven § 10 (jfr. REK nord 2017/1961).

Vilkår:
- DAC forutsetter at prosjektet gjennomføres i tråd med den dokumentasjon som ligger til grunn for godkjenning i REK og HNT, og med de vilkår som er gitt. Innsamlet data skal kun brukes slik det er beskrevet i formålet til det omsøkte prosjektet.
- DAC forutsetter at prosjektet behandler opplysninger i henhold til gjeldende lovverk. Dette innebærer at behandlingsansvarlig institusjon (Nordlandssykehuset) sørger for tilstrekkelig informasjonssikkerhet.
- For ansatte i HMN (utenfor HNT) kreves signert databrukerkontrakt før tilgang til journal kan gis. Det er kun navngitte prosjektmedarbeidere som kan gis tilgang.
- Opplysningene som innhentes skal være adekvate, relevante og begrenset til det som er nødvendig for formålene de behandles for («dataminimering»). Dette innebærer at kun opplysninger som er nødvendige for å svare på problemstillingen, skal registreres.
- Ved eventuell fremtidig gjenbruk av data som er innsamlet i HNT, eller ved større endringer i prosjektet skal dette meldes til DAC.
- Sluttdato for prosjektet er satt til 31.03.2022, men opplysninger skal lagres i fem år etter prosjektslutt. DAC forutsetter at opplysninger slettes eller anonymiseres innen 31.03.2027 og kommer til å be om bekreftelse på dette.

Vedtak:
Prosjektet godkjennes med de vilkår som er gitt.

For søknader der det etterspørres ytterligere dokumentasjon, ber vi om at denne ettersendes postmottak@hnt.no så snart det foreligger. E-posten skal merkes med saksnummer 2020_2507

Kreditering av Helse Nord-Trøndelag HF ved publisering:
Forskningsansvarlig viser til vedlagte retningslinjer for kreditering og acknowledgements ved publisering av artikler som utgår fra eller benytter data innsamlet i HNT. Den korrekte engelske benevnelsen på HNT er Nord-Trøndelag Hospital Trust.

For ytterligere opplysninger ta kontakt med Hege Selnes Haugdahl, forskningsrådgiver, ph.d.
hege.selnes.haugdahl@hnt.no

Behandlet i DAC, 24.08.2020

Med vennlig hilsen

Bodil Landstad, professor
Forskningssjef i HNT

Kopi:
Klinikkleder Carl Platou, Klinikk for medisin og rehabilitering, Sykehuset Levanger, HNT

Appendix 7

Informed consent form for participants (in Norwegian)

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

INNOVATIV FYSIOTERAPI I REHABILITERING ETTER HJERNESLAG I SUB-AKUTT FASE -EN PROSPEKTIV RANDOMISERT KONTROLLERT OG KVALITATIV STUDIE

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å undersøke effekten av to typer fysioterapi når gitt i de 12 første ukene etter utskriving fra slagenhet samt erfaringer med tjenestene. Deltakerne i prosjektet vil bli tilfeldig inndelt i to grupper, den ene gruppe vil få behandling med fysioterapi type A og den andre med fysioterapi type B. Begge intervensjonene er i tråd med nasjonale retningslinjer for behandling og rehabilitering etter hjerneslag. For å få innsikt i erfaringer med innhold og forløp i rehabilitering etter hjerneslag vil enkelte deltakere fra begge grupper bli intervjuet.

Du er forespurt om å delta fordi du har hatt et hjerneslag og er innlagt slagenheten ved Nordlandssykehuset i Bodø eller Sykehuset Levanger som følge av dette. Nordlandssykehuset er ansvarlig for forskningsprosjektet.

HVA INNEBÆRER PROSJEKTET?

Som deltaker i studien vil du etter utskrivning fra slagenhet på sykehus få fysioterapibehandling type A eller B i 12 uker uansett om behandlingen foregår på rehabiliteringsinstitusjon eller i din hjemkommune. Begge gruppene får lik mengde fysioterapi.

Hvis du skal til rehabiliteringsinstitusjon innebærer deltakelse i studien daglig trening med fysioterapeut i inntil 60 minutter på hverdager. I tillegg gjennomføres egentrening i 5-10 minutter i samarbeid med hjelpere eller på egenhånd (5-10 minutter).

Dersom du reiser hjem i løpet av de 12 oppfølgingsukene vil du ha trening hos fysioterapeut i din hjemkommune tre ganger i uka og egentrening 30 minutter per dag tre dager uka. Treningen kan deles opp og vil til enhver tid tilpasses din dagsform og ditt funksjonsnivå.

I prosjektet vil vi innhente og registrere opplysninger om deg. En fysioterapeut, som ikke er involvert i gjennomføring av behandlingene, vil hente følgende informasjon fra din journal: alder, kjønn, type og tidspunkt for hjerneslag, medikamenter/medisinsk behandling, sosial status og funksjonsnivå før slaget.

Videre vil fysioterapeuten gjennomføre tester som undersøker gange, balanse og funksjon i daglige aktiviteter før utskrivning fra slagenheten og etter 12 uker. Det vil bli foretatt målinger av balanse i sittende og stående ved å bruke en trykkmatte som registrerer tyngdepunkt i sittende og en kraftplattform som gjør samme registreringer i stående stilling hvis du greier å stå. Du vil få utdelt en aktivitetsmåler (liten brikke i et elastisk belte) som måler fysisk aktivitet og antall skritt som du skal ha på deg i de første 7 dagene etter testing. Du vil bli bedt om å fylle ut spørreskjemaer som omhandler din opplevelse av egen livskvalitet.

Hvis du ikke har store språkvansker som følge av hjerneslaget kan du bli forespurt om å delta på intervju. Deltakelse innebærer en samtale med en i løpet av oppfølgingsperioden på 12 uker. I intervjuene vil fokus være på hvordan du opplever fysioterapi, innhold, medvirkning og overføringsfasene i din rehabilitering. Intervjuene vil vare ca. én time og vil bli tatt opp og lagret som lydfil.

Informasjonen som innhentes fra din journal og testresultater vil oppbevares adskilt fra dine personopplysninger på Nordlandssykehusets forskningsserver og i et låsbart skap som kun prosjektleder og prosjektmedarbeider har tilgang til.

MULIGE FORDELER OG ULEMPER

Som deltaker i studien vil du bidra til innsamling av data som vi håper å bruke til å framskaffe kunnskap som kan bidra til å kvalitetssikre fysioterapi etter et hjerneslag.

Du vil motta intensiv og individuelt tilpasset trening utført av godt kvalifiserte fysioterapeuter. Det kan ses som en fordel at du er sikret oppfølging i 3 måneder etter hjerneslaget. Treningen er i tråd med de gjeldende nasjonale retningslinjer for behandling og rehabilitering etter hjerneslag. Om du velger å delta i studien eller ikke vil det ikke ha noen konsekvenser for din videre rehabilitering.

Det er ingen risiko ved å delta i studien. En mulig ulempe kan være at testing kan oppleves som slitsomt. Testingen vil imidlertid tilpasses din kapasitet og dagsform og du kan når som helst be om pauser underveis.

Hvis du blir intervjuet kan du bidra med viktig kunnskap om hvordan rehabilitering etter et hjerneslag oppleves fra ditt ståsted. Det vil bli tatt hensyn til at noen opplever at de blir fortere sliten etter et hjerneslag. Det vil også tas hensyn til at noen av temaene som tas opp kan være følelsesmessig vanskelig å snakke om. Du kan til enhver tid si fra om dette og vi kan unngå disse temaene eller sette av tid til å snakke om dette etter intervjuet

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du vil få betenkningstid slik at du kan rådføre deg med andre. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte:

Britt Normann (prosjektleder), britt.normann@nordlandssykehuset.no, tlf: 99614941

Marianne Sivertsen (prosjektmedarbeider), marianne.sivertsen2@nordlandssykehuset.no, tlf: 90536992

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få rettet eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

FORSIKRING

Deltakerne i studien er dekket gjennom pasientskadeloven

ØKONOMI

Deltakelse i studien medfører ingen utgifter for deg ut over den egenandel man vanligvis betaler hos fysioterapeut. Pasientreiser dekker kostnader til transport til og fra testing og behandling hos fysioterapeut.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, REK. (2017/1961)

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato Deltakers signatur

Deltakers navn med trykte bokstaver

Stedfortredende samtykke

Som nærmeste pårørende til _ (Fullt navn) samtykker jeg til at hun/han kan delta i prosjektet.

Sted og dato Pårørendes signatur

Pårørendes navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato Signatur

Rolle i prosjektet