Inequality in Neurorehabilitation

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DIFFERENT PRACTICES AMONG PATIENTS AND RELATIVES DURING REHABILITATION AFTER STROKE AND SEVERE TRAUMATIC BRAIN INJURY: A QUALITATIVE STUDY

BY
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AALBORG UNIVERSITY
DENMARK

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CV

Rikke Guldager was educated as a nurse from Roskilde Amts Sygeplejeskole in 1998. For almost 18 years, she has been working as a nurse and clinical nurse specialist at the Department of Neurorehabilitation, Traumatic Brain Injury unit, Rigshospitalet. While working as a nurse, she obtained a diploma of Health in 2008 from Metropol, Copenhagen. In 2014, Rikke Guldager completed a Master of Science (MSc) in Nursing from Aarhus University with a master's thesis carrying the title *Job satisfaction among nurses in Neurorehabilitation'.* In August 2015, she was enrolled as a PhD student at the Department of Learning and Philosophy at Aalborg University with a focus on inequality in neurorehabilitation, which is also the topic of the present thesis.

Dansk resume

Hjerneskaderehabilitering er en vigtig del af behandlingsforløbet efter apopleksi eller svær traumatisk hjerneskade. Kvantitative undersøgelser har påvist, at privilegerede grupper (målt i uddannelseslængde, indkomst og beskæftigelsesstatus) tildeles flest ydelser i sundhedsvæsenet, mens mindre privilegerede grupper får tildelt færrest ydelser, hvorfor det kan konstateres, at der findes socioøkonomiske forskelle i behandling i sundhedsvæsenet i Danmark. I denne afhandling undersøges, hvorvidt lignende tendenser findes inden for hjerneskaderehabilitering og i givet fald, hvordan denne ulighed i rehabilitering praktiseres. Der fokuseres på individers praksisser under rehabiliteringsforløb efter en apopleksi eller svær traumatisk hjerneskade på to danske rehabiliteringsafdelinger.

Ulighed i rehabilitering belyses ved at stille skarpt på praksisser og strategier, der iværksættes af patienter og pårørende i relation til de involverede sundhedsprofessionelle grupper, ligesom der fokuseres på, hvordan patientens/pårørendes forskellige ressourcer giver adgang til og gennemslagskraft i neurorehabiliteringsfeltet, og hvordan dette potentielt påvirker rehabiliteringsprocessen.

Det overordnede formål med afhandlingen var at udvikle viden omkring rehabiliteringspraksisser primært på mikroniveau (relationen mellem patienter, pårørende og sundhedsprofessionelle) for at forstå, hvilken betydning forskellige ressourcer og ulige baggrunde hos patienter og pårørende kan have for patienters rehabiliteringsforløb. For at undersøge dette blev der gennemført to studier, hvor det empiriske materiale baserer sig på observation og interviews med patienter og pårørende med enten apopleksi eller svær traumatisk hjerneskade. Pierre Bourdieus konceptuelle triade habitus, kapital og felt, samt begreberne strategi, position, positionering og disposition, udgør den teoretiske referenceramme. Resultaterne er præsenteret i tre videnskabelige artikler. Formålet med artikel I var at undersøge, hvordan patienter og pårørende iværksætter deres ressourcer under indlæggelse til rehabilitering efter apopleksi. Studiet blev designet som en kvalitativ undersøgelse af ti patientforløb fra indlæggelse til udskrivelse. Det overordnede resultat var udviklingen af et nyt begreb, en felt-specifik form for kapital: rehabiliteringskapital, der potentielt gavner patienter og pårørende under deres rehabiliteringsforløbet ved at give patienterne en fordel, der sikrer dem det bedst mulige rehabiliteringsforløb. Konklusionen på artikel I var, at rehabiliteringskapital tilføjer en nyt teoretisk komponent, der er med til at forklare visse dimensioner af samspillet mellem patienter, pårørende og sundhedsprofessionelle i neurorehabiliteringsfeltet. Rehabiliteringskapital kan hjælpe med at forstå den nuværende rehabiliteringspraksis samt være udgangspunkt for forslag til forbedringer i klinisk praksis, herunder patient- og pårørendeinddragelse. Formålet med artikel II var at undersøge pårørendes handlinger, strategier og praksisser under mødeaktiviteter og i interaktionen med de sundhedsprofessionelle under indlæggelse til rehabilitering efter svær traumatisk hjerneskade. Studiet blev designet som et kvalitativt studie.

Der blev identificeret tre pårørendepositioner: den opsøgende, den observerende og den afventende position. De tre positioner illustrerer, hvordan pårørendes position og dispositioner har betydning for hvilke strategier, de kan iværksætte. Dette kommer til udtryk i måden, hvorpå pårørende kan involvere sig i og relatere sig til de sundhedsprofessionelle under indlæggelsesforløbet. Konklusionen på artikel II var, at det er vigtigt, at sundhedsprofessionelle er i stand til at kunne differentiere pårørendes forskelligartede behov for information, støtte og involvering. Viden om de tre pårørendepositioner tilbyder en tænkeramme, som klinikkerne kan anvende til at reflektere over egen praksis. Formålet med artikel III var at identificere mulige potentialer og barrierer, som forskelligt positionerede pårørende oplever i forhold til at kunne involvere sig i rehabiliteringsforløbet. Studiet var designet som et kvalitativt studie baseret på to eksemplariske cases. Analysen illustrerer, hvordan pårørendes ulige ressourcer på forskellige måder fungerer som potentialer og barrierer for involvering i rehabiliteringsprocessen. Konklusionen i artikel III var, at mængden og fordelingen af pårørenderessourcer har betydning for de praksisser, som de kan iværksætte og dermed betydning for hvilke potentialer og barrierer, der er for at blive involveret i rehabiliteringsforløb. Dette viste sig i, hvordan deres dispositioner og strategier fik betydningen for deres involvering i rehabiliteringsprocessen. Det er et livsvilkår, at pårørende og patienter har ulige socioøkonomisk og uddannelsesmæssig baggrund og ressourcer, hvorfor sundhedsprofessionelle bør kompensere herfor med ulige praktikker. På denne måde kan sundhedsprofessionelle bidrage til mere lige og retfærdig behandling og muligheder for involvering af alle patienter og pårørende, uanset hvilken position de har i det sociale rum og uanset deres ressourcer.

English summary

Brain injury rehabilitation is recommended for effective treatment and care after a stroke or a severe traumatic brain injury. Quantitative studies show that groups who are privileged (in terms of education length, income and employment) receive better treatment and services, while the less privileged groups receive fewer benefits and services. Examples of disparities in healthcare treatment rooted in Danish citizens' socioeconomic position can also be found. This thesis examines whether such differences exist within brain injury rehabilitation and, if so, how inequality in rehabilitation plays out. Thus, the thesis focuses on practices exercised by individuals affected by stroke or severe traumatic brain injury in the rehabilitation process during hospitalisation at two university hospitals in Denmark.

Inequality in health is illustrated by examining practices and strategies undertaken by patients and relatives in relation to the providers involved and by examining how patients/relatives' possession of differential resources impact their access to and clout vis-à-vis rehabilitation services in the subfield of neurorehabilitation and how this potentially affects the overall rehabilitation process.

The overall goal of this thesis is to develop knowledge about rehabilitation practices primarily at the micro level (relationships between patients, relatives and providers) in order to understand how different resources and unequal backgrounds of patients and relatives may impact patients' rehabilitation processes. To reach this goal, two studies were conducted. The empirical material is based on observation and semi-structured interviews with patients and relatives with stroke or traumatic brain injury. The theoretical framework is Pierre Bourdieu's theory of practice with particular focus on the conceptual triad of habitus, fields and capital; as well as his concepts of strategy, position, positioning and disposition. The results are presented in three scientific articles. The objective of Paper I was to examine how patients and relatives mobilise resources in decision-making in a stroke unit. The study was designed as a qualitative study of ten patients and their close relatives. This study resulted in the development of a field-specific form of capital: rehabilitation capital, which is a resource potentially benefitting patients and relatives during inpatient rehabilitation, and which may provide patients with an advantage, ensuring that they have the best rehabilitation. The conclusion in Paper I was that rehabilitation capital adds a new theoretical component that may help explain certain dimensions of the interaction between patients, relatives and providers. This concept helps us understand current rehabilitation practice and provides a basis for suggesting improvements in clinical practice concerning the involvement of the patient and his or her relatives in rehabilitation care. The objective of paper II was to identify relatives' strategies and practices in the rehabilitation process as seen in their meetings with providers. The study was designed as a qualitative study. The main finding was that we identified three different positions for relatives: the warrior, the observer and the hesitant relative. These positions illustrate how different positions and related dispositions of relatives influence their strategies. Differences were evident in how relatives act, participate and relate to both the patient and the

providers during rehabilitation. The conclusion in Paper II was that it is of utmost importance that providers are able to differentiate relatives' need for information, support and involvement. Knowledge about the three related positions offers a way of thinking that can help clinicians reflect on their own practice. The objective of Paper III was to identify possible facilitators and barriers differently positioned relatives are facing when being actively involved in the rehabilitation process of patients with traumatic brain injury. The study was designed as a qualitative study based on two exemplary cases. The analysis illustrates how relatives' differential and unequal resources function as facilitators and barriers for involvement in the rehabilitation process. The conclusion in Paper III was that different practices related to the amount and distribution of resources among relatives' function as facilitators and barriers for their involvement in the rehabilitation process. Thus, it is a condition of life that patients and relatives have different socioeconomic and educational backgrounds and resources. Healthcare professionals should therefore be able to compensate for these unequal practices and hence contribute to more equal and righteous treatment and opportunity for involvement of all patients and relatives, regardless of their position in social space and their resources.

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‘Research is to see what everybody else has seen, and to think what nobody else has thought’

Albert Szent-Gyorgyi

The quotation from Albert Szent- Gyorgyi was one of the first things I noticed during my stay at the Melbourne Royal Hospital. It struck me how privileged I have been spending the past three years doing research in an area that is close to my heart.

Part of my thesis is based on observation and interview data. I am grateful for the willingness of the providers, patients and relatives who openly shared their stories of experiencing life at an existential turning point. Special thanks are therefore due to all the participants and their families for their important contribution to this study. This research would not have been possible without their participation.

Thank you, staff nurses Vivi Nielsen, Rene Richard Andersen and Helle Dahl Jensen at the Department of Neurorehabilitation, Traumatic Brain Injury and the Department of Neurology, Rigshospitalet, respectively, for being gatekeepers and making it possible for me to attend the meetings.

I feel privileged to have had the opportunity to work as a PhD student at the Department of Neurorehabilitation, Traumatic Brain Injury, Rigshospitalet, Denmark, where I have been employed for the past 18 years. My gratitude goes to my supervisors, who both are the kind of supervisors everybody new in research would wish for. The collaboration between the three of us has always been respectful and rewarding. Kristian Larsen, my main supervisor, you have always been inclusive and appreciative, both on a professional and personal level. I am grateful for all your help, support and for introducing me to Bourdieu. Ingrid Poulsen, my co-supervisor, with whom I have been close during the entire PhD course; I have been truly privileged to always have your support and help. You have always been there for me, both in good times and rough times. I also wish to thank my colleagues and co-PhD students at the Department of Learning and Philosophy, AAU, especially Helle Rønn Smidt, Lone Falck Jørgensen and Mette Ryssel Bystrup. Thank you for your friendship and support; for providing an always supportive and safe environment. It has been wonderful to be with like-minded people, even if we sometimes felt misplaced in the role of PhD students. To the SOUL group, especially Ass. Professor Karin Højberg and Ass. Professor Anette Lykke Hindhede, my thanks are due for constructive feedback and discussions on my work, as well as social interaction at conferences. I would also like to acknowledge the Phlegethon network where it all started. Thanks to all the senior researchers, which whom I have also worked on other research projects relevant to my own research area.

As part of my research, I had the opportunity to visit Allied Health, Melbourne Health, Australia, and I want to thank Karen Willis; you played an important role in making my exchange stay in Australia possible. You introduced me to Aussie culture and were a truly amazing and open person; you also provided valuable contributions for Paper II and III. I also want to thank Marit Solbjør who also played an important role for me during my stay in Australia. You included me in your life and research, encouraged me and made me feel at home.

I would like to extend my appreciation to the managers Christian Pilebæk Hansen and Hanne Munk at the Department of Neurorehabilitation, Traumatic Brain Injury, Rigshospitalet, Denmark, for believing in the project and for all the support including funding of the PhD. A special thank goes to my former staff nurse Vivi Nielsen and head nurse Inge Pietersen for encouraging me to aim for academic training relatively late in life. To all my colleagues at the Department, thank you for always being curious and interested in my research. You are the best colleagues.

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Last, but not least, I thank my parents for teaching me never to give up and for your support. Thanks to my friends for the encouragement and support. I look forward to spending lots of time with you again; to Henrik for being a patient support during my research and preparation of this PhD thesis. To my beautiful sons Gustav and Noah, thank you for your patience and love. This thesis is dedicated to you.

Abbreviations and definitions

ABI	Acquired brain injury, injury to the brain that has occurred after birth but is not related to congenital defect or degenerative disease. The origin can be traumatic or non-traumatic (e.g. stroke)
CAT-scan	Computerised axial tomography
CHC	Cultural health capital
DKK	Danish kroner
DRG	Diagnosed-related groups
FoC	Fundamentals of care
GCS	Glasgow Coma Scale Score
GP	General practitioner
IR	Involving rounds
RC	Rehabilitation capital
TBI	Traumatic brain injury; traumatically induced injury to the brain
Close relatives	The patients' self-appointed closest relatives
Doxa	A particular perception of reality that dominates in a field
High position	Distribution of materials (economic, social and cultural resources)

Interdisciplinary team meetings	Meetings attended by the patient and relatives along with the relevant interdisciplinary team consisting physicians, nurses, nurse assistants, occupational therapists, physiotherapists, speech lingual pathologist and neuropsychologist
Logic	‘The rule of the game’
Low position	Distribution of few economic, social and cultural resources
Primary relatives	The relative who in a legal sense is the closest relative
Providers	Healthcare providers involved in the rehabilitation process; nurse, nurse assistant, neurological consultant, physiotherapist, occupational therapist, neuropsychologist and speech lingual pathologist
Rehabilitation	WHO: “A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”
Relatives	Informal caregiver/family caregiver/primary relatives, defined as family members or friends
Therapy	The act of restoring body functions through physical and cognitive training
WHO	The World Health Organization

List of original papers

This thesis is based on the following papers, which will be referred to by their Roman numerals and are reproduced in the appendices.

Paper I

Guldager, R., Poulsen, I., Egerod, I., Mathiesen L.L., Larsen, K. (2018). *Rehabilitation capital: a field specific form of capital to understand rehabilitation in a Nordic welfare state.* Health Sociology Review.
DOI: 10.1080/14461242.2018.1434808

Paper II

Guldager, R., Willis, K., Larsen, K., Poulsen, I. (2018). *Relatives' strategies in subacute brain injury rehabilitation: The warrior, the observer and the hesitant.* Journal of Clinical Nursing. DOI:10.1111/jocn.14598

Paper III

Guldager, R., Willis, K., Larsen, K., Poulsen, I. (2018). *Relatives' involvement in neurorehabilitation: facilitators and barriers*. (Submitted, under Review).

The papers have been reprinted with the kind permission of the publisher.

During my PhD study, I was also involved in other studies involving research relevant for patients with brain injuries. These studies have resulted in the following papers not included in my PhD thesis. Still, they contribute to the understanding of inequality in rehabilitation and the challenges doing research with vulnerable patient populations.

Guldager, R., Poulsen, I. Ulighed i hjerneskaderehabilitering - menneskers ressourcer spiller ind på sundhedsprofessionelles ydelser. I: Glasdam, S.(red) Folkesundhed - bag om intentioner og strategier. Accepted; to be published at GADS Forlag in September 2018

Guldager, R, Larsen, KB, Poulsen, I. Forskning med patienter uden handleevne: Lovgivning og etiske overvejelser. Klinisk Sygepleje. DOI: 10.18261/issn.1903-2285-2017-02-07

List of figures

List of tables

Table of contents

Chapter 1

The purpose of the first chapter is, first, to present the background for conducting the PhD study, which includes a short presentation of the two patient populations, the organisation of neurorehabilitation in Denmark and a systematic literature review on publications on individuals with stroke or traumatic brain injury (TBI) and/or relatives' experience of the neurorehabilitation process. Then, perspectives on inequality in health will be presented. Finally, the aim of the PhD study will be presented.

Introduction

Throughout my career as a nurse with almost 18 years spent in neurorehabilitation, I have learned how patients with TBI may have very different rehabilitation trajectories. This applies both to the physiological part, such as where the damage is located and the extent of the brain injury, and to the question of how the patients, their relatives and the closest network behave and interact in the rehabilitation process. Through my clinical work, I have experienced how patients' own activities, training efforts, motivation and commitment can influence how effective and active they can be in the rehabilitation process, but also that relatives and friends may be more or less effective and active in the rehabilitation process. For example, patients and/or relatives may be active, direct and outspoken or reactive and passive, which impacts heavily on the rehabilitation process in relation to how it is planned and implemented, and on the types of activities undertaken, etc.

In Denmark, rehabilitation trajectories unfold within institutional contexts harbouring ideals of "free and equal rights to social services" and where "patients' needs" govern the rehabilitation plans. Still, quantitative studies examining differences in the treatment of patients (with stroke or heart failure) from different socioeconomic groups find that differences in care do exist (1). A Danish study from 2014 illustrates some of these differences. For example, social inequality was found in patients' access to and consumption of services. The less privileged patients with the lowest level of education received less treatment (measured in DKK) and for a shorter time (length of stay) than patients with higher incomes and levels of education (1).

Research shows that the more privileged patients and relatives can be very powerful and demanding vis-à-vis healthcare providers, which, unfortunately, is often not the case for patients and relatives with fewer social or other resources. Being privileged and resourceful is typically linked to being in a high social position with economic, social and cultural resources determining one's social position. Low social position, on the other hand, is reflected in the availability of fewer economic, social and cultural resources (1, 2).

The present study examines whether inequality can be found within acquired brain injury (ABI) rehabilitation and, if so, how this inequality in rehabilitation unfolds in the Danish healthcare system. ABI can be traumatic or non-traumatic, caused by a sudden external trauma to the brain or an internal source (e.g. stroke). The present study focuses on strategies initiated by patients and relatives in relation to the healthcare providers (hereafter called providers) involved.

The overall aim of the PhD study was to describe the practices used by patients diagnosed with stroke or TBI and their relatives throughout inpatient neurorehabilitation in general. More specifically, we focus on their experience of the rehabilitation process and how this experience is reflected in strategies they initiate and apply when they interact with the providers during the interdisciplinary

meetings. In this thesis, practices are understood as pre-conscious bodily orientation based on habitus to obtain services or to improve the position in the subfield of neurorehabilitation (2). A qualitative approach is used to understand how patients' and relatives' different practices influence their participation in the rehabilitation process. We use data from observations of interdisciplinary meetings between patient/relatives and providers and from semi-structured interviews with patients with stroke or TBI and/or interviews with their relatives.

The findings are presented in three papers. The objective of Paper I was to examine how patients and relatives mobilise resources in decision-making in a stroke unit. The objective of Paper II was to identify relatives' strategies and practices in the rehabilitation process and how they unfold in meetings with providers. The objective of Paper III was to identify possible facilitators and barriers that differently positioned relatives are facing when being actively involved in the rehabilitation process of patients with TBI. Table 1 provides an overview of the papers included in the present thesis.

Table 1. Overview of study design

	Paper I (Study I)	**Paper II (Study II)**	**Paper III (Study II)**
Title	Rehabilitation capital: a field-specific form of capital to understand rehabilitation in a Nordic welfare state.	Relatives' strategies in subacute brain injury rehabilitation: The warrior, the observer and the hesitant relative.	Relatives' involvement in neurorehabilitation: facilitators and barriers.
Aim	To examine how patients and relatives mobilise resources for decision-making in a stroke unit.	To examine relatives' strategies and practices in the rehabilitation process in meetings with providers and from the perspectives of relatives of patients with a TBI.	To examine relatives' strategies in relation to the healthcare providers when seeking to become involved in the rehabilitation process and to identify possible facilitators and barriers differently positioned relatives are facing in this endeavour.
Design	A qualitative study.	A qualitative study.	A qualitative study.
Construction of empirical data	Participant observation and semi-structured interviews performed between January and February 2016.	Participant observation and semi-structured interviews performed between November 2016 and June 2017.	Participant observation and semi-structured interviews performed between November 2016 and June 2017.
Participants	Ten patients with stroke and their close relatives.	Eleven relatives of nine patients with a TBI.	Eleven relatives of nine patients with a TBI.
Analysis	Qualitative content analysis with an inductive phase (focusing both on the manifest and	Qualitative content analysis with an inductive phase (focusing on the manifest content in	Qualitative content analysis with an inductive phase (focusing on the manifest content in

	latent content in the data) and a deductive analytical phase, applying Bourdieu's conceptual triad of habitus, capital and field.	the data) and a deductive analytical phase where categories guided by Bourdieu's conceptual triad of habitus, capital and field were entered into a descriptive matrix.	the data) and a deductive analytical phase, applying Bourdieu's conceptual triad of habitus, capital and field.
Results	A new theoretical concept to explain certain dimensions of the relation between patient, relatives and providers in the field of rehabilitation.	A new framework for understanding how providers can meet and support relatives in rehabilitation differently in order to meet their (and thus the patients') diverse needs.	Different facilitators (knowledge about patient, proactive, participating in nursing care situations, explicit about own wants and needs, maximal flexibility from workplace, possesses cultural skills that align with the providers) and barriers (reactive, non-participant in nursing care situations, unable to express own wants and needs, time-consuming, minimal flexibility from workplace) to involvement of relatives in the rehabilitation process are identified.
Publication	Published in Health Sociology Review.	Published in Journal of Clinical Nursing.	Under review in Advances in Nursing Science.

Background

ABI, including external trauma such as TBI and internal sources such as stroke, is a global public health problem associated with high socioeconomic costs due to long-term disability and death (3). ABI often has major consequences for the individual affected, the relatives and for society. ABI occurs unexpectedly and suddenly, typically in the event of an accident, such as motor vehicle accidents, working accidents, falls, after violent acts (called TBI), or because of a cerebral haemorrhage, brain thrombosis, cerebral inflammation, encephalitis, anoxia (oxygen deficiency) after cardiac arrest, suffocation or drowning. It is estimated that in Denmark approx. 120,000 people are living with the consequences of ABI (4).

Definition and epidemiology of stroke

Stroke is trigged by an interruption of the blood supply to the brain, mostly because a blood vessel bursts or is blocked by a clot that cuts off the supply of oxygen and nutrients, thereby damaging the brain (5). Stroke can be defined as an ischaemic stroke, an intracerebral haemorrhage or the stroke type can be undetermined (6). Among stroke patients, men are at a slightly higher risk than women. This can be explained by their different lifestyles as indicated by smoking and alcohol habits, dietary and exercise patterns, use of general practitioner (GP) and specialist physicians, as well as stress management (4, 7). Stroke most often affects people over 65 years and the risk of stroke increases exponentially with age (8).

Globally stroke affects an estimated 17 million people (6). In Denmark, the incidence of stroke is 56.5 strokes per 100,000 inhabitants annually (9).
Patients often experience a broad range of physical, functional, psychological and emotional sequela following a stroke, e.g. hemiplegia, communication disorders (e.g. aphasia), fatigue, swallowing difficulties, apathy, depression and anxiety (10). Thus, stroke causes neurological disability, loss of independence, insecurity and reduced quality of life (11). A study from 2014 showed that 75% of patients with stroke experience difficulties with activities of daily living (12). This may have the consequences that when stroke survivors return to home, they are dependent on their relatives. This may put a heavy burden on the relatives, who are often overwhelmed and exhausted, feeling isolated, abandoned and alone (13).

Definition and epidemiology of traumatic brain injury

The causes of TBI are diverse, but TBI is most often due to a motor vehicle accident, violent acts, sports-related injury or falls. The severity of TBI is classified into mild, moderate or severe and mostly measured by the Glasgow Coma Scale (GCS) within the first 24 hours of injury without sedation. GCS assesses the level of

consciousness on a 3-15-point scale. A GCS below 9 is traditionally defined as severe TBI (14), while a GCS between 9–12 is defined as a moderate TBI. Both conditions lead to long-term physical, cognitive, social and behavioural deficits (15). These impairments affect the patient's participation in the decision-making process during admission to a neurorehabilitation department, and relatives therefore become important participants as the patient's voice and as a proxy for the patient (16). The relatives must assist the providers with information about the patient's former abilities and interests so that the rehabilitation activities become both relevant and helpful for the patient (17). About 80% of individuals with TBI rely more or less on caregivers for long-term and life-long assistance due to their many physical, psychological, cognitive, emotional, behavioural and social disabilities (18).

The incidence of TBI varies between studies and countries. In the US and Europe including Denmark, the incidence is approximately 30 per 100,000 persons per years for structural brain injuries and 200 for milder injuries (19). More males are at risk of getting a TBI. Thus, it is estimated that TBI rates are 29% higher in males than in females (20), and the peak age of injury occurs between the ages of 15–24 years and the age of 75 years and older (20). The prevalence in the younger group is most likely a manifestation of a greater degree of risk behaviour (e.g. drug and alcohol misuse) among younger men, while in the elderly TBI is due mostly to falls (20). Since a considerable proportion of the patients who suffer from a TBI are younger, this has significant implications for society because these young people are left with chronic residual neuropsychiatric, cognitive and communication disabilities (20). For example, sadness and depression are some of the most prevalent reactions after a TBI. A study from 2017 shows that 61% of patients get a depression post TBI (20). Survivors after a TBI often suffer from a combination of impairments influencing their ability to function in their everyday life; behavioural (e.g. aggression and impulsivity) and cognitive (e.g. memory and attention deficits) problems are a frequent consequence of a TBI, and these changes may burden the relatives as well (21, 22).

Neurorehabilitation in Denmark

In Denmark, the Danish Health Authorities have two concepts of rehabilitation: "genoptræning" and "rehabilitation", referring to different levels of rehabilitation (23). The English translation of 'genoptræning' is rehabilitation. Thus, the term 'genoptræning' refers to the restoration of body functions through physical and cognitive training; in this thesis, this concept is referred to as therapy to distinguish the two concepts from each other. The term 'rehabilitation' is broader in scope and is defined by the World Health Organization (WHO) as "*a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments*" (24, p:96). In this thesis, the concept of rehabilitation will be used.

To ensure that individuals with ABI are offered comprehensive neurorehabilitation at the appropriate level of specialisation in relation to their rehabilitation and rehabilitation needs, The Danish Health Authorities have outlined clinical pathways for patients with ABI, including levels of specialisation during hospitalisation after a ABI (see Figure 1). Rehabilitation in Denmark is divided into three levels of specialisation; basic level, regional level and highly specialised level. The level of specialisation is determined according to the patients' needs, the volume of patients, the need for professional skills and the need for resources in terms of technology and equipment (23). For example, rehabilitation at the specialised level is characterised by a high degree of specialisation of the rehabilitation offer (e.g. the interdisciplinary staff is educated and trained as specialists and the necessary interdisciplinary staff is available, etc.). The regional level is less specialised and the basic level is even less (23).

The principle that applies in neurorehabilitation is that the more severe and consequently the more complex the brain injury is, the higher the level of necessary specialisation. It could be expected that most patients and relatives desire the most specialised level of care for the affected individual, and the consequences of this may be that compared with less resourceful individuals, more resourceful patients and/or relatives will deploy their greater ability to influence the decision-making process to this end.

Table 2. Levels of specialisation during hospitalisation after an ABI.

Levels of specialisation during hospitalisation after a ABI		
Levels of specialisation of rehabilitation	Patients (relevant for this thesis)	Management of the rehabilitation effort.
Basic level[1]		Most hospitals can manage basic level functions.
Regional level	Stroke Mild TBI	Rehabilitation at a regional level can be managed in one to three hospitals in each region in Denmark[2]. These hospitals manage functions with some complexity, and the rehabilitation effort requires some resources, e.g. collaboration between specialities.
Highly specialised level	Stroke with complex disabilities Moderate and severe TBI	Rehabilitation at the highly specialised level is managed in one to three hospitals in Denmark. These hospitals manage functions with a high degree of complexity, and where the rehabilitation effort requires many resources, e.g. inter-professional expertise, knowledge and collaboration between many specialities.

Organisation of neurorehabilitation in Denmark

In Denmark, all citizens have equal access to tax-funded services, such as public school and health care services, regardless of their sociodemographic characteristics (25). Thus, all patients are entitled to publicly financed inpatient rehabilitation as well as municipal rehabilitation if ordered by a physician or as part of an interdisciplinary rehabilitation plan. Patients with moderate to severe TBI clearly benefit from early hospital-based interdisciplinary rehabilitation (26); and hospital-based, specialised interdisciplinary rehabilitation of a citizen with a stroke has moderate to great effects. These effects are largely attributable to the integrated teamwork and concerted effort of specially trained staff, and to staff education, functional training, early start of mobilisation and training and integrated physiotherapy and nursing (27, 28).

In Denmark, acute stroke treatment and care is centralised in one to six specialised hospitals in each region (29, 30), whereas stroke rehabilitation is managed at one to

[1] In Danish ‘Hovedfunktionsniveau’

[2] Denmark has a total of five regions

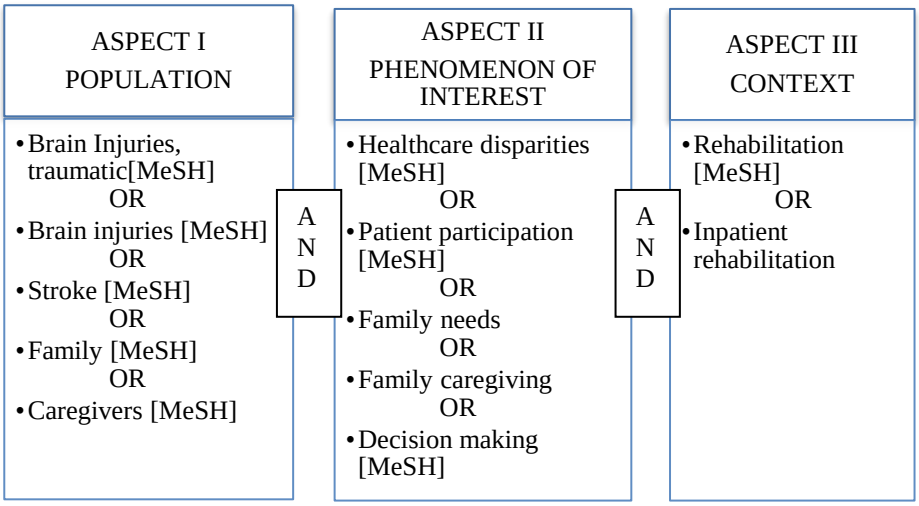
three hospitals in each of the five regions. Patients with stroke are usually admitted to a regional neurological department, where they can also receive rehabilitation until they are stable enough to be referred to rehabilitation provided by the municipality (29, 30). TBI rehabilitation is centralised in two highly specialised departments. One in the eastern part of Denmark, the Department of Neurorehabilitation, Traumatic Brain Injury, Rigshospitalet; the other, Hammel Neurorehabilitation Centre, covers the western part of Denmark. The typical trajectory after the acute phase with a moderate to severe TBI is transition to one of the two specialised departments (31). After finishing inpatient neurorehabilitation, patients are usually referred to further rehabilitation at a municipal or a regional rehabilitation centre or to home training (32). Altogether, rehabilitation after a ABI will be an ongoing process to maintain and refine skills, and it can last from several month to years (33).

Systematic literature review: experience of the rehabilitation process from the perspective of individuals with stroke or TBI and/or relatives

This thesis oscillates between understanding the mechanism that makes patients and relatives act like they do and mapping existing knowledge in a more positivist understanding. In this section, these two different science traditions are joined. This thesis adopts a sociological approach, even if its empirical work is located in the field of medicine which is dominated by an objective science philosophy. A systematic literature review is within this research tradition. If the chosen approach was that of a purely sociological/ social constructivist one, then the ideal of objectivity would not possible to achieve.

The database PubMed was searched from January 2003 to April 2018 to identify papers reporting on the experience of the rehabilitation process from the perspective of individuals with stroke or TBI and/or their relatives. To facilitate a systematic literature search, a PICo model was developed. The PICo acronyms stands for P-population, I- Phenomenon of interest, and Co-context (34) (see Figure 2). In the included papers, the admitted patients had to be 16 years or older and needed to be diagnosed with either stroke or TBI (mild, moderate or severe). In papers addressing relatives' experience, the lower age threshold was set at 18 years and relatives were required to have a close family member diagnosed with stroke or TBI (mild, moderate or severe) to be considered eligible. The following search string was used to retrieve the relevant literature from 2003-2018: "brain injuries, traumatic" [MeSH] AND/OR "brain injuries" [MeSH] AND/OR "stroke" [MeSH] AND/OR "family" [MeSH] AND/OR "caregivers" [MeSH] AND/OR "patient participation" [MeSH] AND/OR "family needs AND/OR "family caregiving" AND/OR "healthcare disparities" [MeSH] AND/OR "decision making" [MeSH] AND/OR "rehabilitation" [MeSH] AND/OR "inpatient rehabilitation".

Figure 1. Aspect analysis



Two trends recurred in the 15 included studies 1) Patient and family needs *during* the inpatient rehabilitation. 2) Patient and family needs *after* discharge from inpatient rehabilitation. An overview of the studies, listed by year, is presented in Appendix D.

Patient and family needs during inpatient rehabilitation

Only few studies have examined patients' and relatives' needs during inpatient neurorehabilitation. Camicia et al. (2018) found that relatives of patients with stroke often focused on their family members' outcome rather than on their own needs. Furthermore, having a healthcare professional approaching them to assess their emotional and physical health rarely happened but would have been welcomed (35). Juminsko et al. (2007) showed that TBI has long-lasting consequences for the relatives and that they face various burdens and have a great need for different kinds of support (36). However, relatives and patients often felt alone and excluded (37), have unmet informational and emotional needs (38, 39), and expressed a need for practical support (36) and family support (39). Furthermore, relatives expressed a need to assist in the provision of care (38), for having unrestrained access to the patient (35) and for making sense of the experience (38).

Conducting a qualitative study, Lefebvre & Levert (2012) found that relatives often had difficulty expressing their needs to providers while the patient was still in the hospital for rehabilitation because they lacked a perspective on the situation. Thus, the relatives expressed a need for quick, honest, intelligible, accurate and coherent information, especially related to diagnosis, prognosis and factors affecting the

prognosis (40). Jumisko et al. (2007) discussed the experience of "being excluded" and highlighted how patients and families felt avoided by staff and had a sense of being ruled by authority. This exclusion aspect also involved patients' and families' unmet informational and emotional needs (37). Relatives experienced a need to feel useful and involved in the rehabilitation process and that the partnership with the providers was real (40). A range of studies support evidence that families and patients have unmet informational needs during the inpatient rehabilitation process, especially concerning prognosis and information about the future and the ability of the individual with TBI to live his or her future life independently of others (38, 40, 41). Other studies describe how families needed to make sense of the traumatic experience and how they took on a caregiving role, wanting to help in the initial stage of rehabilitation. Problems with helping were expressed by families as feeling "being in the way" of hospital staff (37). Relatives experienced an unmet need to know the contact person they should be communicating with while the patient was admitted for inpatient rehabilitation (40). Trust in the staff and the quality of care provided was another element of importance to the feeling of their needs being met (35). Relatives of individuals with TBI also experienced that they needed to be vigilant to ensure the patient's physical and emotional safety during inpatient rehabilitation, which meant that they had to spend a considerable amount of time at the hospital (42).

Patient and family needs after discharge from inpatient rehabilitation

Relatives experience that their needs at the hospital are quite different from those they have after discharge, and they stress the importance that they are informed about what resources they can call upon as new need arise (40). This aligns with the findings of Dillahunt-Aspillaga et al. (2013) and Lutz (2017) who discussed the importance of having knowledge of benefits and services available to patients with a TBI and their relatives (43, 44). Graff et al. (2017) also found that patients and relatives lacked information on where to get appropriate rehabilitation services after discharge, and that they were disappointed with the services provided, if any (45). Relatives also indicated that they often did not know what to expect when the patient got home, because they had never experienced anything similar to the stroke event (44, 46). In addition, it is evident that relatives' needs increased and changed over time (47, 48), because they had to be constantly available to the individual with a TBI (37), and because the severity of the patient's injury changed over time, meaning that the care burden changed, too (16). Furthermore, managing work schedules was challenging (44, 46). Patients and relatives also experienced lack of information after hospital discharge, especially information concerning sequelae and long-term effects (38), and they described feelings of being abandoned and alone with no one to turn to (44). Relatives experienced various levels of burden and that roles were changing and new life forms emerged (37), while the intensity and frequency of services provided in inpatient rehabilitation slowly lessened (47). Many relatives to stroke survivors find themselves in the role of caring for their own children while also caring for a parent who has had a stroke and having at the same time to manage their own personal and professional lives. Balancing these different

needs is problematic (44). A study by O'Callaghan and colleagues illustrates that the relatives' caregiving burden after discharge increased with the severity of the injury (47). Doser & Norup revealed that spouses spend significantly more time taking care of their family member than parents, and reported higher levels of burden, even in the chronic phase (3-6 years) after brain injury (16). Despite carrying the burden of being a caregiver and being familiar with the role as a caregiver, the study by Graff et al. (2017) shows that the patients and caregivers have difficulties navigating the healthcare system (45). Thus, the caregiver is portrayed as a negotiator. The negotiating caregiver is described as helping and overcoming barriers within the rehabilitation field. The study by Graff et al. amplifies other studies finding that patients experience problems with social isolation and stigma and therefore need help (45). After discharge, relatives still reported that they received inadequate information about injury, diagnosis and available services (47). Besides informational need, they needed emotional and financial support (38). Finally, relatives experienced an increased caregiver burden and decreased life satisfaction over time, which must also be recognised; and efforts have been tailored to address these needs and help relatives assume their role as active participants in the rehabilitation while participating in society and maintaining their quality of life (49). In line with that, relatives to stroke survivors felt overwhelmed, isolated and alone once they got home (44).

What is inequality in health?

Inequality in health can be researched at many different levels. Inspired by work in progress by Kristian Larsen, the following section will give a simplified account of levels of inequality and give examples of health inequalities (50). This thesis focuses primarily on the second and fourth level (but also involves the other levels), which are explained below. These two levels concern inequality at the micro-level of the patient/relative-provider relation, including how patients' and relatives' differential and unequal resources are mobilised and exchanged in the subfield of neurorehabilitation.

The first level concerns unequal social conditions and unequal societies, regions and nations: The more equal society (Scandinavian countries), the higher the quality of life and quantity of health for all (51). 'Health concerns policy, not health policy', state and regulation of policy areas (private/public, conventional/alternative, labour marked, housing marked and education marked. The next level outlines patients and relatives' unequal resources in terms of economic, cultural (e.g. education, knowledge, coping strategies in relation to illness), social (e.g. support from family and friends) and health capital (e.g. investments in one's own body) before meeting the healthcare system. The third level revolves around citizens' unequal strategies to seek and access healthcare (e.g. whether, how and when they seek healthcare)**.** The third level leads to the fourth level; citizens' unequal treatment in healthcare, including their ability to deal with the options offered, e.g. examinations, follow-up on treatment. This is also referred to as the eleventh determinant (4). Thus, the healthcare system contributes to inequality in health if the most privileged

individuals get the most benefits despite the intention of equal and free access to healthcare services (52). Finally, the fifth level concerning health promoting and preventive environment, unequal distribution of initiatives; geographical; city and residential areas, ‘in work/outside work’, types of work, leisure activities; school/education.

The three Scandinavian countries (Denmark, Norway and Sweden) emphasise equal and easy access to healthcare. Even so, inequality in health has been demonstrated within these countries. In Sweden, health inequality is even growing. Earlier, Sweden had one of the best life expectancies in Europe and one of the shallowest social gradients (53). Illustrating how inequality shows in health in Sweden, Diaz (2009) argues that the disadvantaged citizens unfortunately are first and foremost the socially vulnerable population groups. However, the actual mechanisms (e.g. health beliefs or lifestyles) that create inequality have not been described (54). Even so, educational level has been associated with the received care, with those with high education having more opportunities and receiving more up-to-date therapy than those with lower education (54). The Norwegian society stands out as one of the most advanced welfare states in the world (55). Still, great disparities are found between indicators such as rich and poor in terms of illness prevalence and life expectancies (55). A Norwegian qualitative study suggests that privileged and more demanding patients receive more attention and perform like ’expert patients’, whereas more hesitant and less resourceful patients are neglected (56). The findings of inequality in health in Sweden and Norway have also been demonstrated in the Danish welfare system, showing an alarming lack of knowledge of how mechanisms of diagnosis, treatment and rehabilitation affect patients across diverse socio-economic strata (52). Inequality in health has been described in relation to diagnosis-related groups (DRGs), with younger vs. older and high-income vs. low-income patients receiving better treatment, and particularly low-education retirees risking receiving inadequate care (1). Socioeconomic status (low versus high) can be understood as the individual’s position in society, comprising factors such as income, education, employment, marital status and social status. Inequality in health has also been described in relation to access and utilisation of services, where patients with support from their relatives gain access to and utilise more services than patients who have no relatives (57). In conclusion, contrary to the declared goals, unequal treatment exists within the Nordic welfare systems. However, these Scandinavian studies have provided neither a thorough description nor a theoretical explanation of the mechanisms behind this equality.

Album, Johannessen & Rasmussen (2017) address another perspective of inequality in health. In a comparative analysis, they illustrate how 38 diseases on a scale from 1-9 were ranked according to how prestigious they would be considered by health providers in general. The results showed a stable pattern over time, but one disease (stroke) changed remarkably, becoming more prestigious from 1990 to 2017. The reason for this increase in prestige is owed to advances in research, technology and treatment, which turned the disease into an acute one. Moreover, the authors argue that disease prestige may influence decision-making in the healthcare service; hence,

this illustrates fundamental evaluation tendencies likely to influence how health providers evaluate other elements of their profession, e.g. patients and relatives (58). Besides, referring to Weber's classic distinction between three interrelated basic forms of social inequality (resources, power and status), Hindhede & Larsen (2018) state that inequality in health shows in how prestigious a disease is within medical institutions and the medical professions (59). Thus, the medical institution and professions contribute to inequality. This is also evident in the case of stroke, which was earlier defined as a low-prestige disease, but which has now become more prestigious.

Through laws, general instructions, regulations and procedures, institutions seem to be unable to compensate for inequality in health in patients with TBI; indeed, they seem to perpetuate and enhance inequalities (59, 60). A similar pattern of treatment disparities related to socioeconomic status has been shown in patients with stroke (61). Socioeconomic position has been associated with the risk for stroke, which is partly due to lifestyle factors such as smoking, alcohol consumption and obesity. However, the effect of lower social position cannot be explained only by known risk factors (62). In a study published in 2018, Bray et al found evidence of wide socioeconomic disparities in the burden of stroke in England. Thus, patients from the lowest socioeconomic group suffered first stroke seven years earlier than those from the highest groups, and low socioeconomic status was associated with a 26% higher adjusted risk of 1-year mortality.[3] Lastly, low socioeconomic status was associated with poorer care (6). Similar findings have been found in a nationwide study from Denmark, which concluded that there is a strong relation between low socioeconomic position and risk of stroke (62).

The issue of inequality in health for relatives has attracted less scholarly attention. Many studies have illustrated that caregiver burden, caregiver stress, anxiety and depression are common psychological problems experienced by relatives (63, 64) and that these health issues can have a negative impact on the patient's outcome (44). Furthermore, research shows that being a female and spouse influences and increases the level of experienced burden (64, 65). To my knowledge, no empirical studies have been conducted on inequality in health for relatives, even if the Danish government's health policy and documents on inequality in health issued by user organisations highlight that involving relatives is important not only in relation to the patient's disease but also to the relative's health and quality of life (66-69).

Summary of the literature review of patients' and relatives' rehabilitation needs and inequality in health

Existing literature is unanimous that more research is required into the needs of patients with stroke, TBI and their relatives both when the patient is admitted to

[3] I am aware that that the empirical data can be different in England and Denmark, but assume that the data are still largely comparable.

inpatient rehabilitation and after discharge. Empirical evidence suggests that information about diagnosis, prognosis, treatment and care needs to be consistent. Furthermore, patients and relatives need support to manage the motional repercussions of the event. Unmet needs can result in a feeling of isolation and feeling misunderstood and unsupported. While some literature addresses the needs of stroke and TBI patients and their relatives, the needs of relatives are often not systematically assessed during inpatient rehabilitation. Moreover, relatives' disparate resources bear strongly on the rehabilitation trajectory.

To our knowledge, inequality in health at the micro-level of the patient/relative-provider relation has not been examined in inpatient neurorehabilitation and has not included relatives' perspectives and practices. This sociologically inspired PhD study contributes with important insight and a multidimensional perspective on the neurorehabilitation process experienced by individuals with stroke or TBI and their close relatives. A sociological perspective can explain inequality in a clinical field by examining if and how the healthcare system contributes to inequality in health despite the intention to provide free and equal access for everyone and despite its ideals about individualised care. The subfield of neurorehabilitation is characterised as a previously low-prestige disease area (stroke), where patients are hospitalised for relatively long periods. The field is relatively professionalised; patients and relatives are vulnerable and challenged, being in a state of crisis with personal and emotional concerns about the patient's prognosis and future. Thus, neurorehabilitation of patients with stroke and TBI provides a window for studying how the Danish welfare state with its institutions and professions handles heterogeneous patient groups with heterogeneous resources. Understanding the practices of adult individuals with stroke or TBI and their relatives is an important step towards supporting and meeting the needs of patients and relatives throughout the rehabilitation process.

Aim

The overall aim of the study was to describe practices among patients diagnosed with stroke or TBI and their close relatives throughout inpatient neurorehabilitation in general. Particular focus is devoted to how patients and relatives experience the rehabilitation process, what strategies they initiate and apply, and when they interact with the providers during interdisciplinary meetings. Furthermore, a key question in this respect concerns how patients and relatives navigate the healthcare system, what strategies they initiate when they interact with the providers during interdisciplinary meetings, and what kinds of challenges in optimising the neurorehabilitation process they encounter.

The thesis consists of two sub-studies and three papers with the following specific aims:

The objective of Study I (Paper I) was to examine:

- How patients and relatives mobilise resources in decision-making in a stroke unit. The paper focuses on the challenges in optimising the neurorehabilitation process encountered by patients and relatives, and the strategies they use.

- The objective of Study II (Paper II & III) was to: Use a theoretical-empirical analysis to identify relatives' strategies and practices in the neurorehabilitation process as evidenced in meetings with providers (Paper II).

- Identify possible facilitators and barriers differently positioned relatives face in being actively involved in the neurorehabilitation process of patients with TBI (Paper III).

Chapter 2

Chapter 2 presents the theoretical framework of Pierre Bourdieu including his notion of habitus, capital and field. Then an introduction to the research design, participants, setting and methods used for analysing the data is given. Finally, ethical considerations and a reflexive account are presented.

Theoretical framework

"Le réel est relationel" (70, p:97)
"The real is the relationel" (2, p:97)

The theory used in this thesis is driven by sociological research within health science, drawing on the work of the French sociologist Pierre Bourdieu and his theory of practice, focusing on the key concepts of habitus, capital and field and his notions of strategy, position, positioning and disposition. These concepts have guided the entire research process from the construction of the observation recording schedule and the interview guide to data generation, analysis and data interpretation. In Bourdieu's ontology, everything is relationally determined, (71) which means that a relational approach is adopted to study social life, where individuals' social position depends on their relation to others in social space. Bourdieu's concepts of capital, habitus and field are defined in this ontology, and they are interrelated in such a way that they make sense only in relation to each other. Bourdieu's theory of practice is considered useful for identifying and analysing social practices as they specifically unfold in a specific institutional subfield of rehabilitation and hence involve socially reproductive mechanisms in the rehabilitation process in the Danish welfare state. Put in other words, using the concepts of habitus, fields, capital and strategy gives us the opportunity to analyse how individuals' practices and actions are both created by and themselves create social structures. During meetings, using Bourdieu's theory of practice in general and his notion of field in particular, we focused on how the individuals' (agents) actions were, how decisions were made, who participated in meeting activities and how the patients and their relatives were involved. Thus, a key concern was how patients' and relatives' economic, cultural and social capitals were accumulated and capitalised into the welfare system's providers in the neurorehabilitation process.

Bourdieu himself never conducted research on health or studied the field of medicine or rehabilitation. However, Bystrup et al. (2018) have recently unravelled the genesis and history of neurorehabilitation in Denmark, referring to other Scandinavian scholars who also used the Bourdieusian concept of field to explore rehabilitation and habilitation in the Scandinavian welfare state (72-74). Bystrup et al. (2018) concluded that the formation of neurorehabilitation is interweaved with medicine as well as pedagogical, psychological and social sciences, thus making rehabilitation a multidisciplinary subfield. This is reflected in diverse rehabilitation approaches and hinders coherence and quality in neurorehabilitation services (75). Thus, they argue that the subfield of neurorehabilitation must be seen in relation to the field of rehabilitation and the dominating field of medicine as well as the political field (75). Pinell (2011) describes the field of medicine as: '*the one that produces legitimate knowledge of and practices in response to disease and, more broadly, health deterioration'*(76, p:118). The subfield of neurorehabilitation, a specific institutional context, is regarded as a market where some capital is considered important, while other forms of capital are inferior. This is believed to be

of importance to the patient's strategies, attitudes and practices and, consequently, the outcome of the neurorehabilitation process. Within each field, individuals (agents) are positioned: '*that is in the distribution of the specific capital, and on the perception that they have of the field depending on the point of view they take on the field as a view taken from a point in the field* (2, p:101). The agents' positions in the subfield of neurorehabilitation (providers-patient-relative) are interrelated with the broader field of medicine and healthcare that also structures the relation, e.g., the physical and organisational context, relations of dominant, language, values, etc. (2).

Bourdieu's concept of field is defined as '*a network, or a configuration, of objective relations between positions anchored in certain forms of power (or capital)*'(2, p:97). Each field has its own logic ('rules of the game'), including the capitals that are at stake in the field, the habitus and doxa (a particular perception of reality that dominates in the field at any given time) evident in people who occupy the field and in the practices that emerge within the field, and which must be comprehended by the researcher (77). Fields can be thought of as social arenas endowed with a specific gravity and force that influence the actions and reactions of social actors who have tacitly agreed to the rules of the game (2). Bourdieu uses the analogy of a battlefield in which participants vie to establish monopoly over the species of capital effective in it (2). In this thesis, the subfield of neurorehabilitation is conceptualised as a subfield of the larger field of rehabilitation and the field of medicine. This implicates that neurorehabilitation, as a subfield of the field of rehabilitation, is dominated by the medical agenda (75).

Bourdieu's theory of social space can be regarded as a model of society. The concept of field makes it possible to place different analytical units in relation to each other. In the present study, this is done by mapping out the objective structures of the relations between patients with stroke and TBI (78), their close relatives and the providers working in the subfield of neurorehabilitation. Bourdieu describes the social space as multidimensional, but simplifies this to three dimensions: capital volume, capital composition and social trajectory. According to Bourdieu, the relatives' position of resources is the starting point for the position of different individuals or social classes in society. In relation to this, Bourdieu distinguishes between three overall forms of capital: economic, cultural and social capital that determine one's social position. The economic capital consists of material wealth, e.g. money, securities, possession of property, and anything else that can be directly converted into money. Cultural capital contains cultural, information-based resources that can be captured using educational parameters, while social capitals are social relations such as good relations and a well-functioning network. Bourdieu uses the concept of symbolic capital, which is a form of capital that can explain the balance of power in a field and which can be traded in a given field; thus, symbolic capital is generated by its recognition in the field (credibility, recognition, status, prestige and personal authority) (79-81).

The Bourdieusian notions of habitus, capital and strategies have been applied and used in both studies as described in detail in all three papers and briefly outlined in the following.

Study I

In Study I, the interrelated concepts of field, habitus, capital and strategies were applied to the empirical data to describe the forms of capital that individuals draw on in the subfield of neurorehabilitation after a stroke.

In Bourdieu's words, habitus is the product of history and experience (82) or a structuring mechanism consisting of '*a set of historical relations "deposited" within individual bodies in the form of mental and corporeal schemata of perception, appreciation, and action'*(2, p:16). Habitus is developed throughout life as the living conditions of the individual change, but habitus does not change radically because it is bodily internalised. Habitus is a capacity to act, think, taste, believe and behave as well as to access available capital within a specific field (2). The concept of habitus enables work to map patients' and relatives' prior assumptions, beliefs and experiences and thereby how habitus influences how patients and relatives handle the rehabilitation process and, furthermore, how habitus can serve as a barrier or potential in the rehabilitation process.

The concept of strategy must be considered as relationally bound concepts of habitus and field, and it refers to the individual's disposition for acting and performing in certain ways, and performing in the right ways (2). Individuals act on a pre-conscious bodily orientation based on habitus to obtain services or to improve their position in the field (2). *The strategies of agents depend on their position in the field, that is, on the distribution of the specific capital(s) and on the perception that they have of a field depending on the point of view on the field as a view taken from a point in the field* (2, p:101). The concept of strategy was specifically used to reconstruct the way patients and relatives maintain or optimise their position in the subfield of neurorehabilitation.

Study II

In Study II, the concepts of habitus, capital, field, disposition and strategy were applied to the data to analyse relations and to explore the relatives' capacity to mobilise their capitals and how they could situate themselves in the subfield of neurorehabilitation.

According to Bourdieu, disposition is the immediate, lived experience of the agents and it explicates the categories of perception and appreciation that structure their actions from inside (2). The concept of disposition was used as an analytical tool to analyse the diversity in relatives' volume and composition of capital and how this

influences their ways of navigating the healthcare system when dealing with disease, their relations to providers, and how they engage in decision-making. Thus, dispositions are concerned with how relatives orientate themselves in relation to the possibility conditions that the field / subfield affords, in casu the subfield of neurorehabilitation.

Materials and Methods

Research design

Adopting a sociological perspective, this thesis uses a qualitative research design to produce, analyse and interpret data. Qualitative research is designed to reflect richness, depth, meaning and complex situations (83), and it is the preferred approach to examine patient's and relatives' social practices and actions in the rehabilitation process through their actions and words (observations and interviews). The study has two parts: The first part involved ethnographic fieldwork with participant observation of interdisciplinary team meetings. The meetings between patient, relatives and providers are understood as social relations (84). The point of departure for the observational study was Bourdieu's "Participant objectivation" referring to: *'observations conducted 'not only to explore the "lived experience" of the knowing subject but to observe the social conditions of possibility, and therefore the effects and limits of that experience and, more precisely, of the act of objectivation itself. It aims at objectivizing the subjective relation to the object which, far from leading to a relativistic and more-or-less anti-scientific subjectivism, is one of the conditions of genuine scientific objectivity'* (84, p:282). Thus, we saw a specific field as a social arena with dominant social positions, power relations, doxa and struggles (84). In the present thesis, the observational study will be referred to as 'participant observation' because this refers to an overall research method within qualitative research and to concepts widely used within health science; yet, participant observation is understood with reference to Bourdieu's underlying premise and contrasting understanding of participant objectivation and how the researcher needs to do' *objectivation of the subject of objectivation of the analyzing subject'*(84, p:282).

The second part of the study involved semi-structured interviews with patients and/or relatives. Thus, the design was the same in Study I and II; Study I explored patients with stroke; Study II patients with TBI. For an overview of the empirical studies, see Table 2. According to Bourdieu, combining participant observation (observation of materialized action) and semi-structured interviews (what is actually being said in an interview) is necessary because informants are not necessarily able to account for their actions because they often have an immediate experience upon which they do not reflect; they simply act on the basis of this experience without being conscious of their actions which are simply taken-for-granted ways of acting

(85). Callewaert (2014) points out that an interview must therefore be combined with an objective description of the social position from which the interviewee speaks, as power structure and habits are physically embedded and therefore often unconscious to the person doing the interview (86). Thus, combining the two qualitative methods enabled us to observe patients' and relatives' habitus (what patients and relatives do in the subfield of neurorehabilitation) and how they explain their own behaviour.

Table 3. Overview of methods and construction of data in Studies I & II

Study	Methods	Construction of empirical data and participants
Study I	Participant observation and semi-structured interviews	Ten patients admitted to inpatient rehabilitation after a **stroke** and their primary relative Observation of interdisciplinary meetings upon: • Admission to neurorehabilitation • Involving rounds (IR)[4] • Discharge Semi-structured interviews of patients (and relatives) after: • Admission to neurorehabilitation • IR • Discharge
Study II	Participant observation and semi-structured interviews	Nine patients admitted to inpatient rehabilitation after a **TBI** and eleven primary or close relatives Observation of interdisciplinary team meetings upon: • Admission to neurorehabilitation • Meetings • Discharge Semi-structured interviews of patients (and relatives) after: • Admission to neurorehabilitation* • Meetings • Discharge

[4] The involving round is the formal, scheduled interdisciplinary meeting

Setting and time of data collection

The research was undertaken in two hospitals within the Capital Region of Denmark. Study I was conducted at a 16-bed neurorehabilitation department for stroke patients at a university hospital in Denmark from January 2016 to February 2016. The hospital has a regional catchment area covering citizens living in the Capital Region of Denmark. Study II was conducted in a 22-bed highly specialised rehabilitation department for patients with severe TBI at a university hospital in Denmark from November 2016 to September 2017. The department is one of two centralised departments providing highly specialised neurorehabilitation. The catchment area is the eastern part of Denmark, Greenland and the Faroe Islands.

Participants

Individuals included in Study I were patients admitted to inpatient neurorehabilitation after a stroke. Ten patients with stroke and their close relatives participated. In three cases out of the ten, the patients were not cognitively able to participate in the interviews. Instead, it was their primary relative in the legal sense who participated, cf. LBK no. 1083 of 15/09/2017(87). Most patients were males, and most of the relatives were males being husband, brother or son. Patients were referred to the neurorehabilitation department from the acute stroke unit. The patients ranged in age from 45-79 years.

The participants in Study II were eleven primary relatives of nine patients with severe TBI. Due to the patients' impaired consciousness, they were not cognitively able to participate either in the interdisciplinary progress meeting or in interviews. There was a majority of male patients, and the participants included one wife, three mothers, two fathers, two partners, one siblings and one daughter. Patients were referred to the neurorehabilitation department from the neuro intensive care unit as soon as their medical condition was stable enough and they could breathe by themselves without a respirator. The patients ranged in age from 18-72 years.

In both studies, patients and relatives were recruited consecutively in collaboration with respectively the charge nurse or the interdisciplinary management group of the neurorehabilitation department using purposeful sampling. We continued sampling until we had obtained a distribution sample with a broad variation of capital in terms of social position as measured by indicators such as education, profession and financial circumstances, as well as diversity in gender and age. We also aimed for variety in terms of biological relationship between patient and relatives. Patients and relatives were 18 years or older and able to read and understand Danish.

Construction of empirical data

Data in both studies were generated using participant observation and semi-structured interviews. The following section describes the construction of the empirical data. The observation recording schedule and the interview guides used in both studies were identical and will described in detail under the section entitled Construction of empirical data in Study I.

Pilot study

According to Harding (2013), it is distinctly helpful to pilot the interview questions and adjust the interview guide accordingly before undertaking a major study (88). Thus, a pilot study was carried out in September-October 2015 to test the feasibility of the observation recording schedule and the interview guide before conducting the main study. Besides, the pilot study gave me some experience and practice in doing semi-structured interviews. One participant and his closest relative (spouse) was followed through specialised neurorehabilitation after a TBI. The patient was a 60-year-old male, academic and acknowledged within the medical field; he was admitted to specialised rehabilitation following aortic dissection. Both the patient and his spouse possessed a relatively large volume and broad composition of capital. The pilot study is thus an example of a relatively highly positioned couple's way of acting and interacting in the subfield of neurorehabilitation; it shows how they managed their positions and what strategies they applied. The pilot findings illustrate how they very successfully used capitals, especially cultural capital and social capital, when interacting with the providers. Moreover, they had a feeling for and could play 'the game'. Further findings revealed that the patient and his relative, who was also familiar with the healthcare system, possessed the doxa, which is useable in the subfield of neurorehabilitation. Hence, they articulated their knowledge and used it in practice and, furthermore, took advantage of it and used it in the rehabilitation process by converting the capital they had accumulated from the field of medicine and put it into play in the subfield of neurorehabilitation.

The observation recording schedule and interview guide had to be changed only slightly to improve the quality of both. The change consisted in adding questions facilitation the construction of patients' and relatives' habitus and practices, e.g. questions about previous experience being in a relative role and questions like 'what were you doing this morning before driving to the hospital?'

Construction of empirical data, Study I (Paper I)

Participant observation

The setting of participant observation in Study I was the formal, scheduled interdisciplinary meeting called an involving round (IR) (89), which is held once a week at a fixed time and which lasts 30 minutes. The observed IRs lasted 10-37 minutes. The aim of an IR was to involve patients and relatives in setting the goals for the individualised neurorehabilitation course and to inform them about the patient's rehabilitation plan. Patients were asked about their interest, so that meaningful tasks could be planned. The relatives were also invited to give input to rehabilitation activities that were likely to be most relevant for the patient. As described in Paper I, the meetings were attended by the patient and their relatives along with relevant physicians, nurses, nurse assistants, occupational therapists, physiotherapists, and, if required, a speech-language pathologist and a neuropsychologist (90).

The meetings were held in a meeting room reserved for IR at the rehabilitation department at the end of the corridor. The room was painted in white, and the floor was grey linoleum. The room was just big enough for a walker or a wheelchair to get around. In the middle of the room, there was a large round table in white with room for 10 people. The chairs were a combination of both dining chairs and stools. At the end of the wall, three work stations with computers were set up. During the meetings, all participants were seated around the table. The patient and the relatives were mostly seated next to the physician, who also chaired the meeting. If the patient had any communicative problems, the speech-language pathologist was seated on the other side of the patient. If not, the seating seemed random. The administrative planning of meeting, day and time was undertaken by the providers. In practical terms, the providers assigned the newly admitted patient to a vacant bed and a scheduled IR time was attached to the bed. The time of the IR could either be from 9-10 am, 10-11 am, 13-14 pm or 14-15 pm, and the meetings were held on Mondays, Tuesdays, Thursdays or Fridays. The time and day were randomly distributed and scheduled without taking into account if this was convenient for the patient's relatives.

To balance being involved in some way while at the same time being in an observing position, the type of participant observation undertaken was 'moderate participation observations'(91). As pointed out in Paper I, I was identifiable to the meeting participants (becoming more familiar to them over time as multiple meetings per patient were attended), but I did not actively participate in the meetings (90).

A theory-based observation recording schedule was constructed before the meetings. The schedule was focused on the relation between patient/relatives and providers

with attention to how the relatives' needs were met (Appendix H). The meetings were recorded digitally and transcribed verbatim. Field notes were taken on the spot and written down as accurately as possible in relation to what was expressed by patients, relatives or providers. Furthermore, bodies moving in institutional contexts and physical contexts related to the field, body language, facial expressions, gestures, mimic and timing were observed. Thirty-five meetings were observed with between one and six patient/relative dyads present at each. The number of meetings per patient was dependent on the patient's length of stay (Table 3).

The observations inspired the subsequent questions for the interviews with the patients and relatives (92).

Through participant observations that contributed objective data, it was possible to reconstruct the mechanisms behind patients' and relatives' actions, thus visualising the objective regularities to which they were subject.

Interviews

Interviews (n= 35, lasting 30-60 min) were conducted with ten patients and/or relatives immediately after or within a minimum of three days after the IR. They were all recorded digitally and transcribed verbatim. Patients who were cognitively able to participate in interviews were given the option to be interviewed together or separately. The number of interviews with each patient or dyad varied from two to six depending on the length of stay. Semi-structured interview guides were constructed based on Bourdieu's concepts and on findings from the literature review to ensure that the interview questions were aligned with the aim of the study (Appendix I & J).

The interview guide had two parts: In part one, questions were asked related to the patient's or the relative's demographic characteristics, viz. age, marital status, educational level, employment status and ethnicity. Furthermore, questions related to the patient's or relative's upbringing and educational background, experience with illness and the healthcare system were asked. These questions were asked to establish their personal life trajectory and to establish their cultural, economic and social capital, thereby obtaining indications of their positions in social space (93). Questions about demographic information did not evoke emotional responses, but gave the interviewer and the interviewee an opportunity to enter into a dialogue. Jacob and Furgerson (2012) suggest that building a good relationship with the participants may facilitate better responses (94).
In part two, questions focused broadly on the experience of the hospital stay and rehabilitation process, examining patients' and relatives' practises in relation to the providers, involvement and information and their actual experience of the meeting. The second part of the interview guide was also used in the follow-up interviews. This interview guide contained specific questions that followed up on the earlier

interviews and was otherwise focused on their experience of the meetings and relation to the providers.

According to Bourdieu, the researcher exposes the interviewee to symbolic violence: '*It is the investigator who starts the game and sets up its rules, and it usually the one who, unilaterally and without any preliminary negotiations, assigns the interview its objective and uses'* (95, p:609). The researcher must therefore '*reduce as much as possible the symbolic violence exerted through that relationship'*(95, p:609). In the interview situation, which in some cases was an emotion-loaded interaction, several attempts to reduce the symbolic violence were made. First, doing the interviews, we sought to minimise the patients' and relatives' potential perception of 'being judged' or 'being guilty', since some of them revealed thoughts about guilt (e.g. being a smoker). This mitigating strategy was pursued through the display of empathy and use of active listening. Second, the interviews were conducted within an ethical framework to gain the interviewee's trust (e.g. being explicit about how the interview would be anonymised through transcription and how citations would be presented in the written text). Finally, the interview guides gave the interviewee an idea about where to go and which path to take, and hence allowed us to reconstruct the patient's and the relative's habitus, their total amount and distribution of capital, as well as their habitual dispositions in relation to past experiences with illness and relation to providers.

Construction of empirical data, Study II (Paper II and III)

The methodology and participants were similar for Paper II and Paper III, and will be described in the following.

Participant observation

In Study II, a total of 23 meetings that were part of inpatient neurorehabilitation were observed. The department had two physically connected wards forming a long corridor. The meetings were held in a meeting room reserved for meetings at the ward where the patient was admitted. The room was painted in soft colours and fitted with a squared table in white and had room for 8-10 people. The chairs were coloured dining chairs. At the end of the wall, computers were set up. During the meetings, all participants were seated around the table. The seating seemed more or less random. The first meeting was on the day of the patient's admission at the department and the administrative planning of the meetings was undertaken by the providers. The relatives were informed at the neuro intensive unit that the meeting would take place and that their participation was expected (96). Ideally, the patient should arrive from the transferring hospital no later than at 10 am for the providers to examine the patient before the meetings, which were held at 11 am. For logistic reasons, this was not always possible. The meetings were scheduled to last 30 minutes and took between 20 and 46 minutes. The meetings involved the patients,

relatives and a neurorehabilitation team involving a nurse, nurse assistant, doctor, physiotherapist, occupational therapist and, when relevant, also a neuropsychologist and a speech-language pathologist. The purpose of the meetings was to discuss the clinical assessment of the patient and the patient's likely prognosis, length of stay and discharge destination. Since most such patients have a decreased level of consciousness upon admission to neurorehabilitation and throughout inpatient neurorehabilitation, they are not able to participate in the meetings. Thus, the relative becomes an expert by proxy for the individual with a TBI. The relatives were asked about the patient's pre-injury abilities, interests and personality.

Field notes were taken during the meetings and were typed into a computer immediately after the meeting.

Interviews

To capture the participant's habitual dispositions and practices in relation to the rehabilitation process, individual semi-structured interviews were conducted with eleven relatives immediately after or within three days of the meeting. As pointed out in Paper II, (96) in one case parents to a young patient participated together in the interview, supplementing and supporting each other. In another case, a divorced parent couple wanted to participate in the study, but was not interested in being interviewed together. The number of interviews with each relative varied from two to three depending of the length of the admission. Interviews (n= 23, lasting 23-140 min) were recorded digitally and transcribed verbatim.

Observations

In Study II, I was present in the department before and after the meetings, doing observations of the relatives' relation to the providers and the situations they experienced. During these observations, empirical data were gathered concerning what kinds of questions the relatives asked, what kinds of information the providers offered and the relation between the providers and relatives in general. Descriptions of the relatives' reactions and relations were documented in field notes as soon as possible after each observation and were analysed as part of the empirical data. Thus, there was no standardised observation recording schedule. Doing observation in the clinic offered me an opportunity to gain insight into the relatives' different practices and how their relations with the providers were throughout the rehabilitation process; these observations were addressed in the subsequent interviews (97).

Table 4. Characteristics of participants and total number of meetings and interviews

Patient id/ stroke	**Gender**	**Age**	**Biological relationship of participating relatives**	**Meetings per patient**	**Interviews per patient**	**Interviewee**
1	Male	77	Son	3	3	Patient and son
2	Female	78	Son	3	3	Son
3	Female	54	None	2	2	Patient
4	Male	69	Son	4	4	Son
5	Male	79	Wife	6	6	Patient and wife
6	Female	58	Son	4	4	Son
7	Female	68	Husband	6	6	Spouse
8	Male	52	None	2	2	Patient
9	Male	64	Wife	2	2	Patient
10	Male	46	Siblings	3	3	Patient
				Total of meetings 35	Total of interview 35	
Patient ID/TBI	**Gender**	**Age**	**Biological relationship of participating relatives**	**Meetings per patient**	**Interviews per patient**	**Interviewee**
1	Male	52	Sibling	2	2	Sister
2	Male	29	Son/Mother	3	3	Mother
3	Female	39	Cohabiting male	3	3	Male
4	Male	38	Wife	3	2	Wife
5	Male	26	Wife	2	2	Wife
6	Male	72	Daughter/father	3	3	Daughter
7	Male	18	Parents	3	3	Both parents
8	Male	59	Cohabiting	2	2	Female
9 a	Male	31	Son/Mother	2	1	Mother
9 b	Male	31	Son/Father	(2)	2	Father
				Total number of meetings 23	Total number of interviews 23	

Data analysis

In both studies, qualitative content analysis in two phases was applied to the empirical data. As illustrated in Figure 3, the analysis comprised a deductive and an inductive phase. Even though the analysis is presented as a linear process, it was an ongoing process, moving back and forth between the two approaches. The computer software system NVivo version 10 (QSR International) was used for saving, reading, organising and supporting the analysis of empirical data material.

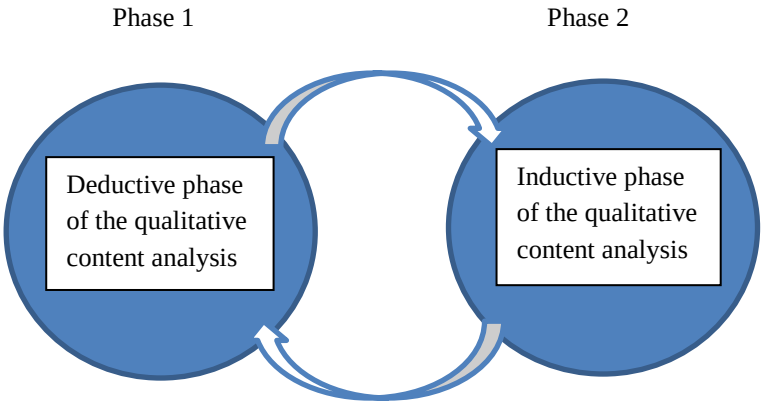
Deductive phase of the analysis

In the deductive phase of the analysis, coding is theory-driven and: '*..codes represent the decisive link between the original "raw data", that is, the textual material such as interview transcripts or field notes, on the one hand and the researcher's theoretical concepts on the other'* (98, p:27). The dispositions and positions of patients and relatives were re-constructed and used to describe and analyse their practices. As an example, disposition was used in Study II (96) to analyse different relatives' diverse capital volume and composition of capital and how this influenced their strategies in the rehabilitation process, while the concept of positions was used to explore how these dispositions performed in the subfield of neurorehabilitation. In Study II (96), a descriptive matrix was applied, which allowed us to categorised data and to observe what appeared (99). According to Miles & Huberman, '*A descriptive matrix in qualitative analysis involves 'the crossing of two or more main dimensions . . . to see how they interact'* (99, p:239).

Inductive phase of the analysis

In the inductive phase of the analysis, *'Coding is a progressive process of sorting and defining and defining and sorting collected data (...) that are applicable to our research purpose. By putting like-minded pieces together into data clumps, we create an organizational framework'* (100, p:133). Thus, a qualitative content analysis was undertaken of transcripts from the meetings and the interviews (101). The analysis followed the procedure for analysing data as suggested by Graneheim and Lundman (101). Furthermore, investigator triangulation was applied at the end of the process to reach agreement on the categories and to minimise individual researcher bias or personal preference in the analytic process and to ensure the confirmability of the study (102). The emerging themes were developed and discussed among the research team until consensus was reached. The purpose of applying this analytical approach was to identify and accept multiple meanings, focusing on the manifest content *'what the text says deals with the content aspect and describes the visible, obvious component* (101, p:106).

Figure 2. The interconnected phases in the analytic process applied in both studies.



Bourdieu's concepts of field, habitus, strategy, position and capital were applied on the empirical data.

In Study II a, the categories were applied into a descriptive matrix

The transcribed interviews and field notes were read several times to get an idea of the visible, obvious components in the text

Important word, sentences and/or repeated contents were marked and noted and meaningful units in the texts were then identified, which is termed the manifest content

The meaningful units in the text, were then inductively coded to identify meaning units and emerging categories in the data.

Ethical considerations

This PhD study was conducted according to the principles of the Declaration of Helsinki (autonomy, beneficence, non-maleficence and justice). Inquiries were made to the local committee of Health Research Ethics, but since the Danish legislation requires no ethical approval for this type of study as it does not involve examination of humans or human biological material, the studies were exempt from the obligation to notify. The study was approved by the Danish Data Protection Agency

(registered under ID 04346) and data were handled confidentially and stored according to Danish law.

One ethical issue identified in this study was patients' lack of capacity to give informed consent to participate in the study as a result of their cognitive impairments. In these cases, the primary relative or a legally acceptable proxy gave the informed consent to participate. Thus, patients (when they were able due to their level of consciousness) or their primary relatives (when they were unable to provide informed consent for themselves) were contacted by the principal investigator and received written and oral information prior to study participation. This information described the purpose of the study, confidentiality, potential risks and benefits of participating, the expected duration of the study, and the voluntary nature of participation and that content could be revoked at any time without any consequences for the further treatment, care and rehabilitation. Informed consent was then obtained from all participants. According to Danish law (LBK no 1083 of 15/09/2017), patients who regain their decision-making capacity and thereby could provide informed consent should be asked to give consent as soon as their condition permits them to do so. In this PhD study, one patient regained consciousness and informed content was obtained (87).

During the rehabilitation process, the patient's condition changed and the relatives' conditions changed accordingly. This meant that their relation to me as an investigator changed throughout the entire rehabilitation process. I was often the only person who had continuous contact with the patient and his or her relatives throughout the rehabilitation process, which made it possible for me to obtain a special, trusting relation to the patient and his or her relatives, which provided valuable information. In a few situations, I asked for their permission to hand over some of the information that came up during the interview to the nursing staff to ensure the best rehabilitation for the patient. Hours were spent with patients and relatives while they were the most vulnerable, which required being sensitive to the participants during the interviews. All patient and relatives expressed that it was a relief to talk about their experiences and that they had an unmet need to talk about it with someone who was neither family nor a friend. Furthermore, they expressed that they found it important to participate in the study to be able to help others in the same situation.

Reflexive account

As I am also a product of the social world, thus pre-constructed, I must, according to Bourdieu, break with my own pre-constructivity and be subject to the same objectivity as that which pertains to the object of analysis. Bourdieu argues:
'*A scientific practice that fails to question itself does not, properly speaking, know what it does. Embedded in, or taken by, the object that it takes as its object, it reveals something of the object, but something which is not really objectivized since it consists of the very principles of apprehension of the object'* (2, p:236).

Reflecting on the social conditions of thinking derived from the researcher's position in social space is particularly important for the ongoing practice of research (93). Bourdieu argues that reflexive sociology is a requisite in empirical research and suggests that three types of biases may blur the sociological gaze: 1) the social origins and coordinates of the individual researcher, 2) the position the researcher occupies and 3) intellectual bias (2). In the following, I will account briefly for this: Since I am educated and socialised into the field of medicine because of my education as a nurse and have extensive clinical experience as a nurse delivering care within TBI rehabilitation, I am familiar with its doxa, and I had access to gatekeepers in the field. This allowed me access to the field and gave me the possibility of accessing and recruiting participants. On the other hand, I was also in an unfamiliar situation because I was a novice to (sociological) research and to the theory of Bourdieu, even if I did become more familiar with the theory and the concepts over time. So, I was somehow trapped in sociology on the one hand and health on the other hand. It has therefore at times been challenging to engage in cross-disciplinary research. I consciously chose to use concepts from health science consistently as headlines, the only exception being 'data collection' which was used as a headline in the published papers written for clinical journals in the field of medicine. In the present thesis, the headline 'construction of empirical data' has been used, illustrating the sociological approach and the underlying methodology of Bourdieu.

The following section will further discuss the challenges encountered while working in a cross-disciplinary way and how I have tried to overcome them. To make sure that my familiarity with the field did not disadvantage the analysis, data were shared with colleagues from other academic professions and backgrounds. This ensured that parts of the data were not overlooked and that the data were not over-interpreted. According to Bourdieu, experience and familiarity with the field of medicine can serve as a *modus operandi* that guides and structures scientific practice (78). Furthermore, inspired by Bourdieu's thoughts on gender, a methodological grasp including two different patient populations may have helped qualify the analysis and given a more comprehensive picture of the practices. Bourdieu stated, "*If one seeks to understand one of the most fundamental aspects of our society and our own culture (e.g. gender), it may be a good idea to study a different community than one's own. It can help break with doxa, the unconscious layer of knowledge that is not questioned, all that is seen as of stock of knowledge or as common sense*". (85 (p:56 my translation), 103).
In addition, in relation to the interview situation, Bourdieu argues that 'true' question will be asked by the researcher having sufficient proximity but at the same time sufficient distance to the field. If there is too much distance to the field being investigated, the researcher will not understand what is at stake and thus not understand the answers. Conversely, there is a danger that if the researcher is too close to the field, there may be much obviousness (doxa); thus, no questions are asked (95). Doxa is the naturalised, taken-for-granted understanding people have of

their social worlds (or fields), their places within these worlds and their perceptions of the social limits and boundaries that exist for them in the world as a result of their life experiences (104).

Thus, a reflective attitude was necessary throughout the research process where I continuously reflected on the steps I took. Research triangulation, for example, involving a team of researchers with different professions and different experiences was made during the analysis to ensure that it reflected the data. In addition, findings from the analysis were presented to colleagues (both other researchers and clinicians), who were not part of the project, for a discussion of their relevance and the reason and logic of the results (see Paper II).

Being a nurse and examining a well-known field and practice did require a reflective attitude and a sociological distance throughout the research process where I continuously reflected on the steps I took, both regarding my position as a researcher and in relation the data I collected. In the following, I will describe the initiatives I took to objectify myself as a researcher, moving between objective and subjective positions:

1) The subfield of neurorehabilitation is constructed as a subfield of the larger field of medicine. Thus, the dominating logic in the former subfield is related to the medical logic that prevails in the latter field. This influences the doxa; for instance, by virtue of my knowledge of disease management programmes, guidelines, standards, diagnosis culture, etc., I am aware that I have chosen to follow this logic and terminology by selecting two patient populations (according to their diagnosis). One of the main arguments for including two different patient populations is the comparative advantage that arises when investigating both a well-known field and an unknown field (insider/outsider perspective).
2) Although I defined my role during the observations as that of a researcher, I was also subject to the condition that the other participants could see me as a former nurse (93). I therefore avoided articulating my employment and profession.
3) I consciously chose to wait in the waiting area together with the relatives before the meetings so that relatives did not identify me as a staff member but rather as an ally or a researcher.
4) Since any field is affected by the presence of an observer and I wanted to disturb the observing field as little as possible, I positioned myself as a moderate-participant observer, articulating from the beginning of the meeting that I should be considered a ‘fly on the wall’. This also meant that I did not carry a uniform and that I positioned myself away from the meeting table, looking at the participants. I also chose this positon to avoid being positioned as a nurse by patients, relatives and providers (93). This, however, implicated a risk of losing capital, because my peers were having difficulties constructing me because they understood me as being part of

the field, resulting in a devaluation of my position (93). This may have impacted the patients, relatives and providers involved in relation to me as a researcher, and it may have influenced which kinds of information I obtained and which interactions I was able to gain access to (93).

5) I was socially very close to most of the providers. According to Bourdieu, this creates shared habitus and the ability to generate questions as well as answers. When a common basis is taken for granted, everything can be said and will be said, except that which is obvious/natural and implicit (95). Thus, I received supervision from a psychologist, with whom I reflected upon my own position as a researcher.
6) Although attention was given to different patients' and relatives' strategies, some relatives were given more time and space in the interviews (relatives from the warrior position), primarily because they were excellent informants, providing detailed information, and needed only little guidance. This showed particularly in the duration of the interviews, highlighting that relatives' social and bodily practices are located and understood as different practices in different social fields; thus, also in the interview situation. The difference between patients and relatives also showed in the nature of the discourse they used. I therefore had to be conscious of the risk of social desirability bias (105).
7) To ensure as objective an approach as possible, I continuously strived to strengthen my educational background by reading theoretical texts and participating in PhD courses and visiting other research environments both nationally and internationally.
8) Finally, much time was spent (more or less) away from clinical practice as a nurse.

Chapter 3

The purpose of this chapter is to briefly present the main findings from Study I, II and III.

Findings

The findings of the two studies (three papers) will be presented in the following

Study I (Paper I)

Study I, which was based on observations and semi-structured interviews with patients and relatives, laid the groundwork for a new theoretical form of capital, rehabilitation capital (RC), and its four associated categories: performative participation (comprises two categories: cognitively embedded performance and self-initiating activities), bodily progression, institutional acceptance and institutional potential (see Table 4). RC is defined as an individual or a family's resources that are cultivated, valued and traded in the subfield of neurorehabilitation as a physical, behavioural and cognitively embedded attitude and practice. RC explains certain dimensions of the relation between patient, relatives and providers at the micro-level in the subfield of neurorehabilitation and explains inequality in neurorehabilitation by offering a vocabulary with which to describe neurorehabilitation practice from a more nuanced perspective.

RC possessed by patients and/or relatives shows itself in the way patients/relatives have the 'correct' attitude, i.e. they are motivated and willing to become independent; they have insight into their own disease and their own limitations; and are therefore able to show progress in the rehabilitation and achieve set rehabilitation goals or even show more effort than the provides had aimed for; and they can act like a 'good patient' and show initiative. These are all performative characteristics that are considered as resources by the healthcare institution and attributed positive value by the providers. RC is a kind of capital that is active and effective in the subfield of neurorehabilitation. Our findings illustrate that when patients possess RC, the providers consider them as active participants because they adhere to the institutional rules, structure and routines; adapt to the logic prevailing in the medical field; and agree with the premises of the healthcare system and therefore do not seem to challenge the providers' professional position or values. In the eyes of the system and providers, the patients' acceptance of the system and the rules of the game is a more important resource than the amount of economic, cultural and social capital. Acceptance of the medical logic and willingness and motivation to help provide care accumulate into a form of symbolic capital that is recognised by the providers irrespective of the patients' socio-economic circumstances and position in social space. The symbolic gift received in return is a better relationship with the provider and more benefits and privileges, e.g. more examinations (e.g. CAT scans, specialist referrals) and access to trainings facilities.

Table 5. Theme, categories and sub-categories

Main theme **Rehabilitation capital**	
Categories	**Brief description of sub-categories**
Performative Participation	
Cognitively Embedded Performance	The patient's body must perform in a proper manner, willing to become independent and have insight into their own disease
Self-initiating Activities	The patients must demonstrate initiative in the rehabilitation process, showing motivation and ability to self-train
Bodily Progression	Institutional and biomedical expectations of the patient's progress concerning the physiological body
Institutional Acceptance	A set of behavioural components patients must possess to be considered as "a good" patient with the 'correct' attitude.
Institutional Potential	An overall rehabilitation potential the patient needs to possess in order to recover within the institutionally defined time frame

Another finding was that inequality in neurorehabilitation existed in the distribution of illness, access to the healthcare system, treatment and the overall rehabilitation process. Individuals who can activate their social capital (family, friend and network as well as their cultural capital (education, workplace) are advantaged because they can convert the fundamental kinds of capital into RC. Surprisingly, even if individuals have a relatively low volume of capital, they are able to draw on their habitual dispositions where motivation, training towards a goal and not giving up are activated during the rehabilitation process. Sociologically, this shows that training mode can be seen as part of a habitual disposition. Thus, an important point is that in the subfield of neurorehabilitation, we see a conversion of the values of cultural, social and economic capital into RC.

The empirical data also contained examples of patients who did not show motivation, progress in neurorehabilitation, initiative and rehabilitation potential, and who did not adapt to the structure and logic of the system. In these cases, it appears that the relatives' volume and composition of capital, especially cultural capital, may compensate for the patient's lack of performative characteristics. For example, relatives could compensate for the patient's lack of initiative and progress in various ways by being present daily in the department, training themselves with the patient, ensuring that the patient did not lie in bed and helping the patient with toilet visits and eating, etc. In this way, the relatives play an active role. Apart from performing necessary tasks, they may also have decisive influence on how providers interpret and treat the patients. It is not (only) the amount of economic and cultural capital that is crucial to the rehabilitation services provided by providers. The amount of social capital is important, too. This implies that a group of patients will be at particular risk of unequal treatment in the subfield of neurorehabilitation, viz. those who have a relatively low volume of capital and no relatives to compensate for this, and who therefore depend on the providers to compensate for the lack of resources in the specific disease situation.

Inequality in neurorehabilitation manifests itself throughout the rehabilitation process, where patients who have a stronger position and better prerequisites to adapt to the medical logic in the healthcare system possess the performative characteristics and therefore get the best treatment and care. Furthermore, there are indications that patients and relatives whose values are more or less in accordance with the healthcare agenda and who are able to perceive, adapt and be socially positioned in the same way as the providers potentially get better treatment and more benefits and services than people who are unable to read the ‘rules of the game’, e.g. because they do not understand the information given to them why they do not ask questions, etc.; the latter group is therefore unable to position themselves as care providers in the social space.

To summarise, Study I indicate that inequality in neurorehabilitation of patients with stroke exists. Those who do not possess performative characteristics and the RC requested by the healthcare system do not get the same services and benefits as more resourceful patients and relatives. Another important finding was that RC is bound to the relatives as a family credit, which means that relatives can compensate for a patient’s lack of RC. This points to the fact that RC makes a distinctive difference for the patient’s rehabilitation process and that inequality in health with differentiated practices and positions among patients and relatives may lie at the root of the unequal treatment observed.

Study II (Papers II and III)

Paper II

Study II included eleven relatives of nine patients with severe TBI with impaired consciousness. A total of 23 meetings were observed and 23 semi-structured interviews were conducted. The findings revealed three relative positions in neurorehabilitation; the warrior, the observer and the hesitant relative. The findings provide a deeper understanding of how providers should meet and support relatives in rehabilitation differently to meet their and thus the patients' diverse needs. The positions should not be understood as predetermined typologies, since many relatives harbour elements of all three, but more as theoretical constructs or positions with common characteristics. The warrior is characterised as being proactive, direct, outspoken, persistent and fully engaged in the decisions about care, and directing the processes to maximise the benefit for his or her relative. The observer is collaborating with and helps providers and is interested in doing whatever providers suggest as being in the best interest of the relative. The hesitant relative is characterised as being primarily reactive and passive in the decision-making processes and uncertain of his or her role. These characteristics are expressions of the relative's habitus as expressed in different reactions and behaviours when their loved one becomes ill; it is therefore very important to consider the relatives' habitual dispositions in order to determine their desire to be involved, the level of involvement and to respond to the individual relative's needs and resources.

A key finding was that the warrior, the observer and the hesitant relative had diverse needs for information, support and involvement during the rehabilitation process. Our findings suggest that patients and relatives differed in terms of habitus, which was seen in their dispositions and clearly different possibilities and needs for being involved.

The findings highlight that an awareness of differences within the relative position gives providers a framework that will ultimately allow them to offer more equal treatment and care in the rehabilitation process. The findings suggest that providers in neurorehabilitation are in a position where they can meet the needs of relatives to individuals with a TBI if they are aware of the different relatives' positions and are able to deploy this knowledge in a flexible and creative manner.

To summarise, Paper II identified three relative positions, the warrior, the observer and the hesitant relative. The positions illustrate how different relative positions and their related dispositions influence the strategies used by relatives of patients with a severe TBI; these strategies show in how they act, participate and relate to both the patient and the providers during the rehabilitation process.

Paper III

The main finding, illustrated with two exemplary cases, indicate how differently positioned relatives' practices, behaviours and strategies becomes facilitators and barriers influencing their ability to be involved and gain advantages in rehabilitation processes. The two cases, presented as Anne and Martin, represent different social positions; one of the cases has a relatively high amount of social, economic and cultural capital, while the other has relatively little social, economic and cultural capital.

Relatives whose social position give them medium to high economic, cultural and social capital seem to have better opportunities for being involved in the rehabilitation process than those with less such capital. This is evident in the possibility they have for being present in the day and night-time, the relationship with the providers and their dedication and proactivity. Contrary, the opportunity for relatives whose social position give them relatively low to moderate economic, cultural and social capital seem restricted in their knowledge about the patient.

Paradoxically, the findings illustrate that Martin's opportunities for being involved (being proactive, participating in nursing care situations, being explicit about own wants and needs, obtaining maximal flexibility from his workplace, and possessing cultural skills that align with those of the providers) were mainly Anne's barriers to being involved (reactive, non-participant in nursing care situations, unable to express own wants and needs, time-consuming, minimal flexibility from workplace). This was evident in her relation to the providers, her possibility for being present, non-participation in nursing care and her difficulties expressing her need for information. Martin's barriers to being involved consisted in Martin being simply too proactive.

This study sheds light on providers' unintentional reproduction of inequality where those with fewer resources get even less and those with the most resources get even more. This unintentional reproduction of inequality may be counteracted if providers do not take into account barriers faced by patients and relatives regardless of their individual resources and social position. Providers need to recognise the relative's knowledge of the patients; the relatives are experts on the patient's history and life role. As experts in brain injury rehabilitation, providers need to draw on relatives' knowledge and to integrate this knowledge into the organisation of the rehabilitation process to maximise the rehabilitation outcome for the patient. Furthermore, findings from this study may help support relatives cope with in an altered life situation.

To summarise, Paper III outlined different practices related to the amount and distribution of relatives' resources that may be either facilitators or barriers for involvement in the rehabilitation process and are expressed in relatives' habitual dispositions and strategies. Paper III also shows that providers find it difficult to

devise strategies to compensate for the least resourceful relatives' lack of resources and therefore do not involve these relatives as much as the relatives wish.

Chapter 4

This chapter discusses the findings of the two studies and the implications of the empirical findings. Finally, the methodological considerations including the strengths and weaknesses of the overall study will be discussed.

Discussion

General discussion of findings

The overall aim of the study was to describe different practices among patients and relatives focusing on how patients and relatives navigate the healthcare system, what strategies they initiate and when in relation to the providers in the interdisciplinary meetings and what kinds of challenges they encounter in seeking to optimise the rehabilitation process.

The discussion of the findings will be divided into three overall themes: Development of a new form of capital, 'Be like us and you will receive treatment', and patients' and relatives' involvement.

Development of a new form of capital

In Paper I, we propose the existence of rehabilitation capital (RC) as a special form of symbolic capital, conceived in line with Bourdieu's concept of strategy (2) and Shim's concept of cultural health capital (CHC) (106). According to Bourdieu: *'a capital does not exist and function except in relation to a field: it confers a power over the field, over the materialized or embodied instruments of production or reproduction whose distribution constitutes the very structure of the field, and over the regularities and the rules which define the ordinary functioning of the field, and thereby over the profits engendered in this field'*(78, p:39-40). Assuming this view, RC can be interpreted and understood as a field-specific form of capital. First, one might question whether neurorehabilitation is a field with its own logic, rules and regularities. In 'Towards a Reflexive Sociology', Bourdieu stated that the question of the limits of the field is *always at stake in the field itself* (78, p:100) and that the boundaries of the field can be determined only by empirical investigation (78). I have not conducted an analysis of the subfield of neurorehabilitation in Denmark myself, but build on the understanding and analysis provided by Bystrup et al. (2018). As already stated, Bystrup et al (2018) concluded that the subfield of neurorehabilitation is related to the field of rehabilitation and the even larger and dominating field of medicine in which autonomy is governed and challenged by economy and politics. Thus, I argue that the field of rehabilitation can be considered a relatively autonomous field with its own logic, rules and regulations; (2) however, the subfield of neurorehabilitation has a relatively short history marked by increasingly formal organisation and specialisation of rehabilitation practices, services and knowledge institutions (75).

One might question if and how Bourdieu's concepts can be developed empirically and in what sense a resource can be considered capital. Bourdieu argues that: *'The use of open concepts is a way of rejecting positivism – but this is a ready-made phrase. It is, to be more precise, a permanent reminder that concepts have no definition other than systematic ones, and are designed to be put to work empirically in systematic*

fashion'(2, p:96). In an interview with Loic Wacquant, Bourdieu said: *'I never set out to "do" theory or to "construct a theory" per se… There is no doubt a theory in my work, or, better, a set of thinking tools visible through the results they yield, but it is not built as such* (78, p:50). Thus, Bourdieu argues that: *'"Theories" are research programs that call not for "theoretical debate" but for a practical utilization that either refutes or generalizes them or, better, specifies and differentiates their claim to generality'* (2, p:77). It is evident from these statements that Bourdieu claims that it is necessary to overcome the dualism between theoretical and empirical knowledge. Thus, I argue that doing empirical research, testing Bourdieu's concepts empirically and analytically, the development of a new field-specific form of capital is justified by the finding that the conventional forms of capital did not resemble the kind of resources we saw unfold in the field of neurorehabilitation. Still, this does not imply that every source or resource that cannot be classified as symbolic, economic, social or cultural capital is necessarily a distinct form of capital that needs to be named. Still, RC can be distinguished from other types of capital because of its unique characteristics: RC is not unequivocally related to class; it can be characterised as capital because it can be converted into other kinds of capital; it can be invested in the field to gain benefits; and it can complement or build on the conventional forms of capital (107). In this perspective, RC becomes a resource available for some patients and relatives (agents), and it can be interpreted as an empirically verified resource that enables the possessor to leverage advantage in the rehabilitation process.

It can be discussed which significance RC may have for the power relations between patient/relatives and the providers. We may consider RC a field-specific form of capital, just like symbolic capital, and if RC is capitalised and converted into symbolic capital and hence becomes recognised as legitimate by the providers, this allows for power and dominance to arise. According to Bourdieu, there is a risk that symbolic violence occurs when an agent draws on his or her symbolic capital (85). Cultural capital has been linked to advantages and disadvantage in health, healthcare utilisation and healthcare behaviours (108). Bourdieu argues that symbolic violence is an instance of misrecognition[5] or lack of insight; and that misrecognition is the opposite of recognition[6], realisation, appreciation and gratitude. The dominating actor (providers) perceives the dominated actors (patients and relatives) through categories that arise in response to dominance and, consequently, are aligned with the interest of the dominant actors (85). This underscores that patients and relatives who do not possess RC and/or cultural skills that align with those of the providers are at risk of getting worse/unequal treatment for this reason alone, and the providers (agents) are not conscious of this reproduction of inequality. This means that the providers are part of this doxa and any presuppositions that exist in the field, and they thus convey symbolic violence. The possibilities for breaking the symbolic dominance will, according to Bourdieu, require a double naturalisation, first, of what

[5] In French méconnaissance

[6] In French reconnaissance

is laid down in the physical space and, second, of what is embedded in the body, for example bodily reactions (109).

Finally, other researchers have developed new forms of capital while examining inequality in health. These forms of capital underpin, supplement and differ in various ways from RC. Generally, these forms of capital have common characteristics, e.g. they originate from cultural capital and most of them are field-specific forms of capital. As mentioned in Paper I, (106), Shim has developed the concept of CHC rooted in Pierre Bourdieu's notion of cultural capital to help account for how the patient-provider relation unfolds in ways that may generate disparities in health care in the U.S. Within the context of health care, Shim defines CHC '*as the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal healthcare relationships'* (106, p:1). While some patients may successfully apply and accrue CHC and use it to their own advantage, others are less likely to do so because of their lack of resources (e.g. to capitalise on language, skills to communicate, medical knowledge, etc.). This can potentially lead to inequality in health because providers can solicit, evaluate, shape and foster CHC. Providers do not only respond to the CHC the patient mobilises; they also contribute to their ability to do so (e.g. by communicating to them what kind of actors they can be) (106). In some ways, RC is consistent with CHC, being a field-specific form of capital, developed in and through the repeated enactment of health-related practices. However, RC extends the concept of CHC being applied within a specific institutional context and being disease-specific. Larsen developed the concept of 'health capital', a form of capital that explains new forms of distinctive practices among certain social groups and individuals and which varies within and among social classes (50). Scambler and Newton have developed the concept of 'personal capital' *borne from systematic exclusion from existing forms of capital, and the sequestration of available capital in the field by expert systems that leave parents with an acutely aware, reflexive stance rooted in responding to 'everyday' lifeworld'* (110, p:130). Like RC, personal capital is '*field-specific, disease-specific, temporal and non-transferable in nature but crucial to the ability to act within this temporary, temporal field'* (110, p:145). Finally, Able explains the relationship between material and nonmaterial resources for health using the concept 'health-relevant cultural capital' defined as '*as the culture-based resources that are available to people for maintaining and promoting their health. Health values and norms, health knowledge and operational skills have been identified as key elements of health-relevant cultural capital'* (111, p:3).

'Be like us and you will receive the best treatment'

Viewing the findings in the light of inequality understood at the micro-level of the patient/relative-provider relation, including the patient's and the relative's ability to credit the options offered by the provider or in other words how patients' and relatives' differential and unequal resources are mobilised and exchanged in the subfield of neurorehabilitation, it seems like the findings presented here challenge

some of the understandings of inequality presented in previous research, primarily quantitative studies. This will be discussed in the following section.

In Study I, inequality in neurorehabilitation manifested itself throughout the rehabilitation process, where patients who had a stronger position and better prerequisites to adapt to the medical logic the healthcare system prescribes and who possessed the performative characteristics got the best treatment and care. We expected to find a link between inequality in health and social class, where those individuals with few resources and little capital got poorer treatment and care, as has also been revealed in previous research (112-114). Following the development and empirical testing of the concept of RC, we were surprised and pleased to see that social, cultural and economic capital was not as crucial as anticipated for the ability to gain specific attention from the providers. Instead motivation, a proactive attitude, ability to self-train, display of bodily progression and rehabilitation potential were performative characteristics considered to be resources that could be converted in the subfield of neurorehabilitation and which created advantages that succeeded over other types of capital (social, economic and cultural capital) that are advantageous but not crucial within the specific field of neurorehabilitation. This may be explained by the patients/relatives comprehending the shared set of opinions and beliefs of the field. This aligns with the findings of Scambler & Newton, who conducted a study focusing on the experiences of parents caring for their children with Batten disease. In this study, a new form of capital, 'personal capital', was identified; and the study illustrated how *this personal capital allows the person to reject, harness, filter and 'trans-value' other forms of capital to circumvent them in favour of their immediate circumstances, as well as personal and personalised concerns in the lifeworld* (110, p:130).

Inequality in health also seems to be experienced by patients and relatives with relatively many resources and much capital. First, there is a trend towards giving credit to patients and relatives demonstrating the expected engaged attitude and asking questions considered appropriate by the providers, and to pay this credit only in the form of provider praise (verbalised during the meetings) and through rewards (e.g. access to training facilities outside the formal therapy schedule, and more physical examinations). Second, if patients and relatives are too proactive or reactive, this may have the opposite effect. It is a key lesson that the practices of patients and relatives must align with the logic in the field, which is evident in the distinct practice of being active, seeking, asking and practicing but without challenging institution, professions, knowledge forms too much. In Study II, this was evident in several ways. First, individuals with relatively much capital also experience unequal treatment if they did not follow 'the rules of the game'. In Paper III, this was shown in the example of how a too proactive approach was perceived as a barrier. If patients and relatives question the views and ideas advocated by the dominant positions of the field, they are at risk of being judged by providers as difficult relatives, who are demanding, critical and taking up the providers' time, which potentially takes away time from other patients. This is what Bourdieu calls heterodoxa, which represents a challenge to the status quo of the field (59, 115).

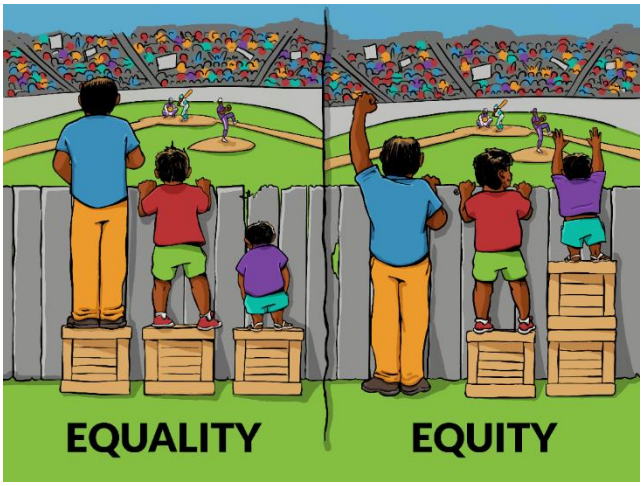
The findings of the present study enhance our understanding of previous results showing how economic and social resources contribute to inequality in health in general and how cultural capital is a key element in the behavioural transformation of social inequality into health inequality in particular (111). Still, even among patients who do not possess RC but draw on social capital instead to compensate for their lack of RC, elements of inequality in health do exist. In such cases, social capital was beneficial because it meant that those who had RC gained access to more rehabilitation services. Furthermore, while the headline in this section *'Be like us and you will receive the best treatment'* might appear a bit provoking, it is, nonetheless, a perspective that allows us to understand the origins of inequality in health. Hence, our findings indicate that patients and relatives whose values are in accordance with the prevailing health agenda and who are able to perceive and adapt and are socially positioned in the same way as the providers potentially get better treatment and more benefits than people who are unable to read the 'rules of the game' in the same way and therefore cannot position themselves as the providers in the social space of neurorehabilitation.
This correspond with the findings of Willems et al. (2005), who illustrated how patients' socio-economic status influenced the doctor-patient communication and how this often disadvantaged patients from lower social classes (114). This observation of an inequality mechanism is in agreement with our findings. Hence, individuals without the characteristics valued by the institutions and the providers were in a restricted position; they may not have understood what was being said to them and therefore asked no questions; therefore, they did not receive the same relevant and adequate treatment as those patients who had these characteristics and were therefore in a stronger position and better understood the information given. This implicates that providers need to understand and be aware of their own position in the field. They may well be so, but probably only subconsciously because they are in a dominant position, occupying a higher social position within the field where their actions are shaped by their habitus (e.g. nurses and allied health professionals are mostly coming from a middleclass background) (116). Furthermore, this may influence their perception of the relatives (being in a dominated position), who somehow come to lose habitus because they are in an unknown field dominated by a medical logic and its rules and regularities. This awareness is important in order to avoid perpetuating existing inequality in healthcare interactions.

If the providers working within the healthcare system want to involve patients and relatives, their involvement must have some clinical relevance. It is essential for improving the delivery of healthcare services to everyone that providers adapt their offer of involvement in care and treatment to the individual patients and his or her relatives (117). As illustrated in Figure 4, the ruling equality ideology in treatment and care practically maintains or even contributes to inequality. To avoid inequality, unequal terms must be meet with unequal practices and individualised offers. Future efforts should therefore focus on promoting providers' awareness of how to individualise involvement without regard to socio-economic status in order to reduce health disparities. If individual concerns are not taken, there is a risk that relatives

will be under such pressure that this affects their quality of life to such an extent that they cannot, for example, take care of their work, which may result in an economic downfall (118). Most relatives are interested in maintaining and using their professional experience/skills, having good colleagues and a proper income (69).
In practice, many different types of relatives may be present in the clinic at the same time, having different needs for support, information, guidance and involvement. This may challenge the providers who must prioritise their time and resources, and this diversity among relatives may challenge the partnership/collaboration between the relatives and the providers. If such challenges occur, knowledge about different relative positions can be used as an analytic tool to uncover the need for information and involvement, among others.

The findings presented in this thesis can be seen as an example of inequalities in society and how these inequalities affect or enhance inequality in health care.
In principle, there is equal access to health in Denmark, but if this is to be operationalised in practice, initiatives must be initiated to support patients and relatives with the fewest resources. This requires that healthcare providers are given tools to resolve these differences (54). Moreover, there is a great need to clarify the need for help and support among patients and relatives who are most vulnerable (e.g. being in a low social position reflected in the distribution of economic, social and cultural capital). This is extremely complicated because many ideological and political games are at play, e.g. the ideal of 'free and equal rights to social services' which implicates that treatment and care are already tailored and individualised.

Figure 3. Equality versus Equity



(This image is free to use: Interaction Institute for Social Change | Artist: Angus Maguire)

Patient and relative involvement

In Denmark, involving patients and relatives is considered desirable and appropriate, and it is required according to existing health policies because relatives' support and resources contribute to better treatment for patients; (119) affect the physical, psychological and emotional well-being of patients; (120) and ultimately have a positive impact on the safety of patient care (121, 122). This thesis shows how complex and multifaceted involvement of patients and relatives is, and it attributes this complexity and multifactedness to the fact that involvement is understood differently depending on individual ideologies, circumstances and needs; thus, different approaches are required to involve patients and relatives. Besides, as described in Paper III (123), there are many facilitators and barriers to involvement. Involvement of patients themselves and their relatives has changed over time, and is today motivated mainly by the shared decision paradigm and the current shortage of financial resources in the healthcare system (124). The current understanding of patients' and relatives' involvement reflect general developments in society (125). The British sociologist Tony Walter (2007) refers to three ideal types of development that reflect the historical changes from traditional, modern and postmodern (126). The three relative positions identified in Paper II reflect the social positions that exist in the Danish society. Thus, I would argue that patients and relatives from the warrior position represent a new kind of citizen who requires involvement and partnership and who is expected to be responsible for his or her own health and healthcare choices. Højgaard and Kjellberg (2017) underline that it is necessary to see relatives as a resource for society, which will require citizens to take more responsibility for their own health in the future, and it will be expected that the resourceful citizens are active and involved in their own illnesses (125). In this way, the warrior becomes a coveted position for the healthcare system and the providers. Relatives taking the warrior position were considered primarily, but only to a certain extent, as a resource. This illustrates a dilemma where individuals with the greatest resources should ideally take more responsibility for their own care and providers should pay more attention to individuals with fewer resources. Paradoxically, it seems that the opposite occurs as relatively privileged relatives gain more attention from providers, meaning that time and attention necessarily go from relatives with relatively fewer resources. In this way, if the intention of involvement is to relieve the system, the providers can unintendedly reproduce inequality in care and treatment.

This increased demand for involvement of both patients and relatives has resulted in the establishment of new user organisations in Denmark (127). User or patient organisations have traditionally been low-positioned in health, but over the past 30 years they have acquired more power (128). As an example, a relatively new organisation, 'relatives in Denmark', was established in 2014. This organisation offers relatives a voice and provide services and help for its members. Within the subfield of neurorehabilitation, two user organisations are seeking to influence the political agenda, The Brain Association (Hjernesagen) and The Danish Brain Injury Association (Hjeneskadeforeningen). These two user organisations speak the voice

of both patients and relatives, and seek to influence the decision making of politicians, healthcare institutions and the public in general (127). For example, the Chairman of ’Hjernesagen’, Lise Beha Erichsen, has proposed a legislative initiative to introduce family medical care leave days to relatives because, as she argues, relatives' effort must be recognised as important and indispensable, and their involvement may be a burden to them when one of their loved ones is hospitalised. Relatives are hidden patients themselves; they have their own needs and suffer physical and mental health consequences from a physically and emotionally demanding work as caregivers and reduced attention to their own health and health care (129). Relatives are often working, caring for other dependents and managing other daily tasks at the same time (44). If these different positions and roles are not aligned and the role of being a relative overshadows being an individual with own concerns, there is a risk of overburdening the relatives; a situation that may develop into a depression (130, 131). Furthermore, relatives are asked to attend meetings, often within normal working hours, which means that they may need to use vacation days to participate. Erichsen points out that this has major social, occupational and economic consequences for the individual relative, but also for society at large. Since relatives are in a dominated position, with no power to make decisions, the time of the meeting is non-negotiable. User organisations are in a position to raise such issues and play a key role in promoting their members’ interests and influencing healthcare policy to accommodate relatives’ needs for involvement (127). In this perspective, the proposal to enact the right to family medical care leave days proposed by a non-profit organisation seems to be able to help reduce or alleviate the dilemma many relatives experience between being actively involved and at the same time having a working life. In Study II, it was found that this was mostly a problem for the hesitant relatives who experienced less flexibility from their workplaces. Authorising such leave days through enactment might help reduce this inequality so that relatives in a relatively low position could get the same opportunities as more resourceful relatives, attending meetings without fear of losing their job.

The three relative positions presented in Paper II illustrate that relatives have different conditions, opportunities and needs for being involved in care and treatment, and hence not the same ability to engage in the rehabilitation process (96). Willems et al. (2006) argue that patients and relatives who are better at communicating and asking questions are provided with more information and are more involved in decision-making (114). For providers to become better at involving patients and relatives, they must be able to identify and relate to relatives’ different needs and resources, and they must acknowledge that some relatives have special needs for support, while others have more resources and may qualify the patient’s rehabilitation process by contributing their knowledge. This is a task that challenges the providers’ professional ability to engage in an equal, mutual, safe and trusting relationship, which is important for promoting active participation. This implicates that providers sometimes must let go of their professional expertise and involve the relatives’ family expertise. Optimally, providers and relatives should co-create professional and family knowledge and expertise for the benefit of the patient.

Nurses are around patients and relatives 24/7 and therefore well positioned to establish a trustful relation and to ensure safe, affordable and respectful care (132). This can be considered a core nursing competency (133). The conceptual framework for nursing called Fundamentals of Care (FoC) could provide a framework within which to discuss and guide how tailored involvement could be created from the time the patient is admitted to hospital. FoC comprises three core dimensions: statements about the nature of the relationship between the nurse and the patient within the care encounter; the way the nurse and the patient negotiate and integrate the actual meeting of the fundamentals of care; and the system requirements that are needed to support the forming of the relationship and the safe delivery of the fundamentals of care (132). FoC aims to improve the quality of health and social care for adults (132). In Paper III, it is suggested that involvement of relatives with relatively few resources who are at the same time in a vulnerable position requires that nurses take a professional responsibility and provide the time needed to create a trusting relationship (123). It could be of interest in further research to build on the findings of different relative positions and the element from FoC, focusing on the establishment of a positive relationship between the nurse and especially the vulnerable patient/relatives with relatively few resources. Thus, findings from Study II suggest that involvement of relatives from this position is not only neglected but also complex and challenging. The relationship must be established based on the nurse's professional level of knowledge, practical skills and ability to engage in dialogue with the patient and his or her relatives; a dialogue and relationship that may be challenged if meetings are short, interrupted or rare. To establish a relationship includes five core elements, explicitly communicated by the nurse to the patient; focusing, knowing, trusting, anticipating and evaluating (132, 134). Establishing a trusting relation with patients and relatives at the very beginning of hospitalisation may contribute to improved practices of involvement in the rehabilitation process, where involvement is based on identification of the relative's needs, and where support could thereby be delivered in a way better tailored to the patient's and the relatives' needs.

Methodological considerations

This thesis presents the results of qualitative studies. Qualitative research seeks to gain new insight and knowledge in a systematic way (83). The methodological rigor of this thesis rests on trustworthiness and fulfilment of four quality criteria as suggested by Lincoln & Guba (102) and Kazdin (83), which will be discussed under the following headings: credibility (similar to internal validity in quantitative research), transferability (similar to external validity in quantitative research), dependability (reliability) and confirmability (objectivity).

Credibility

Credibility refers to the believability and plausibility of the findings. This was ensured by sharing raw data within the research group and by analysing the data and reaching agreement on themes, categories and findings together. Before patients

were included in the study, it was discussed in the research group whether they would, indeed, be relevant to the aim of the study. Moreover, credibility was achieved by ensuring maximum variation, making sure that participants differed from each other in as many aspects as possible, e.g. gender, age, biological relation, capital volume and composition of capital. However, in Study I, nine out of ten participants were men; Study II on stroke patients counted four women and six men. This is apparently due to coincidence, since studies show a preponderance for female relatives caring for stroke survivors (135). The number of participants in qualitative research is often smaller than in quantitative research since generalising to a larger population is not of interest (136). According to Bourdieu, it is important to select the right individual or those individuals who seem to be able to contribute to elucidate the underlying construct; indeed, one agent's participation is enough if only that is the right participant (95). In qualitative research participants, are instead recruited until data saturation has been reached (137), which happens when adding more participants gives no additional insights (138). In the present study, data saturation seemed to have been achieved after inclusion of ten and eleven participants in Study I and Study II, respectively. Furthermore, the use of both observation and interviews and interviewing the same participants several times lent further credit to the argument that data saturation was reached following inclusion of 19 patients and 17 relatives.

Transferability

Transferability refers to the extent to which the findings are limited to the subfield of neurorehabilitation or if they may be transferable to other settings, cases or groups (139). In the context of the present thesis, transferability was ensured by providing rich contextual information; giving detailed information about the criteria for the selection of participants and their characteristics, and for how the empirical data were constructed and the analysis conducted; and by adopting a reflexive position on the researcher's role in the research process. The research was conducted in the subfield of neurorehabilitation, and the findings apply only to this field. It is often questioned whether and how it is possible to generalise in qualitative research (102), which, of cause, also applies to the generalisation of the construction of three relative positions based on eleven participants in the present thesis. However, no such generalisation was sought; indeed, the present study's purpose was not to investigate the incidence of a given phenomenon, but to reveal patterns in patients' and relatives' practices and how these practices were related to the situations in which they unfolded in the meeting with providers in neurorehabilitation. The results are based on comprehensive and in-depth analysis of observations and interviews with eleven relatives, which made it possible to enhance our understanding of different relatives' strategies in neurorehabilitation.

Dependability

Dependability refers to how stable the findings are over time and under different conditions. The research design, the construction of empirical data and the data

analysis involved the research group (two senior researchers and myself) and did not change over time. A thorough description of the research process, e.g. how the empirical data were constructed, provides an opportunity for others to challenge the process and the findings of the study. This was achieved by presenting the research process (e.g. method, data and findings) to other research colleagues and to experienced clinicians within the subfield of neurorehabilitation. Dependability also refers to the notion that the researcher and the participants are interrelated and interacting and thus also influence each other (140). This has been described in more detail in the section ‘ethical considerations’.

Confirmability

The notion of confirmability is often used to evaluate the validity of a study and to which extent an independent researcher can generate the same findings. Thus, in qualitative research, the analysis of similar cases to replicate the findings will most likely not be the same as key influences change (e.g. field, relatives, patients, providers). Therefore, to achieve confirmability, triangulation must be performed, which in the present case consists in utilising different data sources, i.e. by combining observations and interviews. Conformability was also ensured by including two different patient population and interviewing them at different time points. Finally, Kazdin argues that confirmability reflects replicability of the findings; (83) still, as stated earlier, replicability is most likely impossible within qualitative research.

Considerations concerning strengths and limitations

To summarise on the methodological considerations, the present thesis has both strengths and weaknesses. The research design made it possible to examine the practices of patients and relatives in the subfield of neurorehabilitation by objectifying these practices using Bourdieu’s theory and concepts. Bourdieu's theory was applied as a theoretical premise and a methodological tool from the very beginning and guided the research process. This may have impacted on the study’s result; however, it is important to note that an interaction between a deductive and an inductive approach was sought throughout the entire research process. When a qualitative analysis is theory-driven, the starting point is a deductive approach, (141) which is probably the most frequently used approach in social science research (142). Thus, applying a deductive approach has strengthened the results of the present study, since theories constitute general statements in a specific field (143). The opposing argument is that a deductive approach may have implied a risk of hampering the exploration of a new phenomenon and conducting an objective analysis, which may have biased the results of the research (141). However, as argued earlier, the aim was not to investigate a given phenomenon, but to reveal patterns in patients’ and relatives' practices and how these practices were related to the situations in which they arose.

As far as the construction of empirical data is concerned, it is a strength that two methods, observation and interviews, were combined as discussed in Chapter 2. In this context, it was a particular strength that patients and relatives could be interviewed immediately or very soon after the interdisciplinary meetings. This ensured that their experiences were as close to how they experienced the meeting as possible and that retrospective interpretation was minimised. Nevertheless, things may have happened (e.g., the patient getting better or worse) between the meeting and the interviews that may have affected the participants and indirectly the data collected.

Chapter 5

This final chapter presents a conclusion and elaborates on the implications for practice and offers recommendations for further research on relatives' involvement in neurorehabilitation.

Conclusion

This study describes different practices among patients diagnosed with stroke or TBI and among their relatives throughout inpatient neurorehabilitation. We focused on how patients and relatives experienced the rehabilitation process, what strategies they initiated and applied when they interacted with the providers during meetings and how this affected the strategies applied in the decision-making processes. In this sociologically inspired study, relations were mapped using data from moderate participant observations and semi-structured interviews with ten patients' and/or relatives with stroke and eleven relatives to patients with a severe TBI. Qualitative content analysis was used to identify categories, sub-categories and themes. The main findings are presented in three papers and have been interpreted and discussed under the headings *Development of a new form of capital, 'Be like us and you will receive treatment'* and *Patients' and relatives' involvement.*

First, we propose a new concept, rehabilitation capital, RC, which is a form of symbolic capital that is translated into efficient practices in the subfield of neurorehabilitation. RC remains unrecognized by providers as it is part of the doxa in their field. This introduces a risk of symbolic violence and reproduction of inequality in clinical and institutional processes of rehabilitation, where patients and relatives possessing RC are better prepared to adjust to the 'rules of the game', thus potentially accessing benefits and services not available to those without RC. Moreover, strategies for action in a field extend far beyond the possession of relevant capital and the unconscious direction of a set of preformed dispositions. Surprisingly, Study I illustrates that economic, social and cultural capital was not as important as expected in the rehabilitation process. The study also shows that patients and relatives with relatively little capital could still be in possession of RC and thereby obtain more attention from providers and more benefits in the rehabilitation process in general. These results implicate that in order to avoid reproducing inequality in health, providers working in neurorehabilitation should have a particular focus on those patients and relatives who do not possess the conventional forms of capital, those who do not have relatives who can compensate and/or those who are not in possession of RC. The findings of this study can help providers working in neurorehabilitation become aware of their own practices. Providers should do their utmost to show interest in patients' and relatives' resources and interests to motivate them and hence create the best possible rehabilitation process.

Second, this study proposes a new framework for understanding relatives' positions in rehabilitation. Relatives may take the role of warrior, observer and a hesitant relative. Our findings illustrate relatives' different possibilities for being part of the rehabilitation process due to widely different prerequisites for understanding the system and its premises. This new framework offers a way of thinking that can help clinicians reflect on their own practice and support them in the relation and meeting with differently positioned relatives. Nurses are around patients and relatives 24/7

and therefore have the opportunity to relate to relatives both formally (the scheduled interdisciplinary meetings) and informally (at the bedside, one-to-one with patient and/or relatives). This informal meeting seems to be particularly important because experience shows that having a voice and being taken seriously by the providers can relieve some of the distress that relatives experience. These findings may help educate providers in how to meet and support relatives in neurorehabilitation differently to meet their (and thus the patients') diverse needs. Nursing care establishing a trusting relation with patients and relatives at the very beginning of hospitalisation may contribute to improved practices of involvement in the rehabilitation process, where involvement is based on identification of the relative's needs, and where tailored support could be delivered.

Third, the findings offer a deeper understanding of how important, yet complex, it is to provide tailored involvement for patients and relatives in the rehabilitation process. Patients (and relatives) are taught to be responsible for their own treatment and health, but not all patients and relatives are able to manage these individualised responsibilities. It appears that professionals with middle class background dominate the subfield of neurorehabilitation and that patients and relatives outside these socio-economic strata challenge the providers (e.g. being either reactive or proactive), which may create barriers for active involvement. Thus, overcoming these barriers requires education, experience and that provides take responsibility for entering into professional collaboration on patients' and relatives' premises. This also requires that providers acknowledge that patients and relatives are not equal in terms of their prerequisites for understanding information, decoding 'the rules of the game' and the dominant norms and culture in the field, and able to take responsibility for their own treatment and health. Providers may have the potential to create fair and equal possibilities for every individual to be involved in the rehabilitation process by providing differentiated offers and services.

Implications for practice

The three papers have different implications for practice, which will be discussed below.

Paper I: Rehabilitation capital

> RC is a theoretical concept that may help explain unequal practices and treatments at a micro-level in healthcare institutions. Providers working in neurorehabilitation need to be aware of patients' unintentional failure to adhere to expectations due to stroke or other diseases.

Paper II: Relatives' positions in neurorehabilitation

> Knowing that involvement of relatives in the rehabilitation process correlates with better outcome for patients and that relatives have different needs for support and wants for involvement in the rehabilitation process has several implications for practice. There is a growing political pressure

for involving patients and relatives in care and rehabilitation, and this should be reflected in the education and training of doctors, nurses and allied health professions. Findings suggest that especially the hesitant relatives need more focus and help from providers because they do not ask for help, information and support themselves. However, this is in no way tantamount to claiming that they do not have as many needs as relatives who are able to express and articulated their needs. Having a broader and more differentiated view on relatives and the different kinds of help and support they need has implication for how clinicians meet, interact, communicate, involve and provide relatives of adult patients with ABI with different types of information and support.

The finding of different relative positions may also help clinicians reflect on their own practice.

Paper III: Facilitators and barriers for involvement

Findings from this study suggest that gender and biological relationship could potentially influence involvement. It could therefore be interesting to specifically study relatives with different gender and biological relationship, e.g. sibling, spouse or parents in a Scandinavian context. The hypothesis is that it might make a different whether one is male or female and if you are a parent or a spouse.

Recommendations for further research

To verify the applicability of RC and to test its wider application in other rehabilitation programmes (e.g. cardiac or lung disease rehabilitation), additional research should be conducted. Such studies could, for example, explore RC in relation to outcome measures through quantitative questionnaires.

Study II contributes to existing knowledge on involvement of patients and relatives. The knowledge is primarily provided from the relatives' perspective. Building on this knowledge, three relative positions were identified, which contributes with a theoretical framework to understanding how providers should meet relatives' and patients' diverse needs. However, there is still important areas to explore in further research:

- Further research needs to develop and test an (nursing) intervention in sub-acute neurorehabilitation with a focus on engaging relatives based on their values, preferences and needs, and as a direct support for the relatives (to minimise caregiver burden) and indirect support for the patient (to improve outcome). Several qualitative studies have identified that relatives of patients with TBI wish to be involved in care and treatment, but no studies have yet been tested and validated in Denmark that systematically identify

relatives' different preferences and needs for involvement in the rehabilitation process and take into consideration their diverse resources.

- Referring to the above-mentioned point, future research should focus on the development, piloting, evaluation and implementation of a tool that ensures systematic, tailored intervention during neurorehabilitation and follow-up of relatives' diverse needs and resources. It is expected that a standardised tool can ensure that relatives' resources and needs are systematically identified and that it can be instrumental in providing services and support aligned with their preferences and needs for being involved while taking their new life situation into consideration. This is expected, in both the short and the long term, to improve relatives' satisfaction and the patients' rehabilitation processes.

- A cost effectiveness analysis could be conducted to analyse whether the intervention leads to a more informed and improved clinical practice.

- As part of developing of a nursing intervention, it could be valuable to invite former patients and relatives with diverse background to become co-researchers. Their contribution would add their perspectives on the needs and preferences in the rehabilitation process, which would qualify the development and test of the tool.

- In this Ph.D. study, relative positions were developed mostly based on relatives being a partner or a spouse. It could be relevant to include relatives with other biological relations, for example explore the sibling perspective, which seems underexposed in this study and in the research literature in general. Further investigation into how different biological relationships and backgrounds may influence the burden, changes in relationships, roles and responsibilities in a family structure and in their daily life with each other would be relevant.

Other relevant research areas:

- Further research should be conducted on patients' and relatives' practices five years after discharge after stroke or TBI, in particular with a focus on quality of life. It could be of interest to do follow-up interviews of the participants included in the two studies presented in this thesis to study if their practices and strategies change through the rehabilitation trajectory and in the meeting with the municipalities.

- Findings from this study revealed that providers have difficulties in involving differently positioned relatives. This issue calls for further

investigation on nurses' perspectives on facilitators and barriers in involving differently positioned relatives in the rehabilitation process. Such research could help identify the nurses' competency level and be conducive to the design of educational programmes tailored to increase their knowledge and enabling nurses to adjust to patients' and relatives' diverse needs, wants and ability to be involved. Such studies may be either qualitative and/or quantitative and should include nurses working with different patient populations within rehabilitation.

- Further research should integrate different relative positions with elements from FoC to optimise quality in the basic aspects of care, including patient-centred care and involvement (as discussed earlier).

- Study II suggested that the way the meeting is organised in the rehabilitation department after a TBI created a barrier and a dilemma for some relatives. User organisations have suggested to implement family medical leave. Further investigation is required into how organisational changes and potential family medical leave influence the relatives' quality of life, sickness absence, patient safety, unintended incidents and the prevalence of anxiety and depression.

- This Ph.D. study has mapped patients' and relatives' practices in two different diagnosis groups within neurorehabilitation. Further research could make a comparative analysis of the differences, similarities, resources and relations in the rehabilitation process between the different rehabilitation practices in these patient groups. Further research could also include doing a comparative analysis within the Scandinavian countries.

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List of Appendices

Appendix A Paper I

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Rehabilitation capital: a new form of capital to understand rehabilitation in a Nordic welfare state

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Rehabilitation capital: a new form of capital to understand rehabilitation in a Nordic welfare state*

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ABSTRACT
Social, educational and health related equality is an ideal in the Nordic welfare states. However studies have shown that well-positioned patients achieve better treatment and more services, for example time and examinations, than others do. This article examines how patients and relatives mobilise resources in decision-making in a stroke unit. In particular, it focuses on the challenges in optimising the rehabilitation process faced by patients and relatives, and the strategies they use. Data were generated using participant observation and semi-structured interviews. Qualitative content analysis was applied to investigate the patients' and relatives' experiences of decision-making. We present a field-specific form of capital: An individual or a family's resources that are valued in the field of rehabilitation as physical, behavioural and cognitively embedded attitudes and practices. Rehabilitation capital consists of four closely interrelated components: Performative Participation (Cognitively Embedded Performance and Self-initiating Activities), Bodily Progression, Institutional Acceptance and Institutional Potential. It is a resource potentially benefitting patients and relatives during inpatient rehabilitation and may provide patients with an advantage, to ensure the best rehabilitation. The possession of Rehabilitation capital (high or low) contributes explanations for unequal practices and treatments at a micro-level in healthcare institutions.

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Bourdieu; inequality; providers; qualitative research; rehabilitation; stroke

Introduction

Stroke is a major cause of complex disability and death worldwide (Adamson, Beswick, & Ebrahim, 2004; Lou, Carstensen, Jorgensen, & Nielsen, 2017), and presents a major health care issue, with over 15 million new cases every year (World Heart Federation, 2017). More than five million survivors are left with a disability requiring rehabilitation (World Heart Federation, 2017). Rehabilitation is a recommended part of effective

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treatment and care after a stroke (Bernhardt, Godecke, Johnson, & Langhorne, 2017), enabling survivors 'to achieve and maintain optimum functioning in interaction with their environment' (World Health Organization, 2011, p. 96). International clinical guidelines for stroke rehabilitation are directed at ensuring the best quality in treatment and care (National Institute for Health and Care Exellence, 2013; Royal College of Physicians, 2016; Stroke Foundation, 2017; Sundhedsstyrelsen (Danish Health Authority), 2011a). Nonetheless, there is unequal access to, and utilisation of, rehabilitation services (Jaffe & Jimenez, 2015; Odgaard, 2016).

The basic principle of the Danish welfare system is that all citizens have free and equal rights to social services. In Denmark, a number of services are free of charge and available to all citizens (for example education and healthcare) (Ministry of Health, 2016).The declared goals of the Danish health legislation are to ensure respect for the individual, his or her integrity and self-determination, while meeting the needs for easy and equal access to the healthcare system, high quality treatment, continuity, free choice, easy access to information, transparency and low waiting times (Retsinformation, 2012). Thus, after a stroke everyone has equal rights to treatment and care in a rehabilitation facility. However, stroke has been documented as one of the diseases with the largest social inequality in Denmark (Sundhedsstyrelsen (Danish Health Authority), 2011b). Andersen, Dalton, Steding-Jessen, and Olsen (2014) illustrates this in a Danish study showing a 30% lower survival rate for low income patients than for high income ones (Andersen et al., 2014). With regard to rehabilitation for traumatic brain injury, being female, older, and unemployed prior to the injury, were predictors for not being hospitalised for highly specialised early rehabilitation (Odgaard, Poulsen, Kammersgaard, Johnsen, & Nielsen, 2015).

Inequality in health, however, is not a new problem. It has been stated that it is avoidable and presents an international challenge (Wilkinson & Kemmis, 2015; World Health Organization, 2003). Inequality remains an issue in the Nordic countries, even though healthcare is mostly financed through taxes and universal health care is provided (Ministry of Health, 2016; Sveriges Kommuner och Landsting, 2009). For example, it has been demonstrated in Denmark that younger and higher income patients receive better treatment than older, low-education patients (Geckler & Hansen, 2014). In Norway, a study has shown that privileged and more demanding individuals act as 'expert patients' and receive more attention, whereas more hesitant and less resourceful patients are neglected (Brænd, 2014). It is claimed that there is an alarming lack of understanding about how healthcare systems contribute to the production of inequality in terms of what takes place in rehabilitation practice at the micro level (relationships between patient, relatives and healthcare providers) and in relation to diagnosis, treatment and processes of institutionalised rehabilitation at the organisational level (Kamper-Jørgensen & Rasmussen, 2008). Studies have shown that professionals and their institutions inadvertently sustain inequality, but we still need to describe the concrete mechanisms behind this phenomenon (Geckler & Hansen, 2014). The aim of our study was to examine how patients and relatives mobilise resources for decision-making in a stroke unit. We investigated the challenges involved and the strategies applied to optimise the rehabilitation process by describing the interaction between patient, relatives and healthcare providers (hereafter called 'providers') at the individual as well as the organisational level.

Theoretical concepts

The sociology of Bourdieu (Bourdieu, 1992; Bourdieu & Wacquant, 1992) focuses attention on a triad of concepts: habitus, capital and field. This triad enables analysis of the relationship between agency and structure (Shim, 2010). According to Bourdieu, habitus is composed of a system of dispositions, embedded within the individual that designate the individual's way of being. Habitus is a capacity to act, think, taste, believe and behave as well as to access available capital within a specific field (Bourdieu, 1990).

Bourdieu's concept of capital can be understood as individuals' resources, which can be deployed when necessary, for example when illness occurs. Capitals are dispositions that can be put into play at a cognitive or bodily level when agents in the field strive to maintain or improve their position or prevent its devaluation (Bourdieu & Bennett, 2010). Bourdieu (1986) argued that capital can present itself as three fundamental types: economic capital, cultural capital and social capital (Bourdieu, 1986). Economic capital refers to an individual's material resources such as income and properties. Cultural capital is about an individual's educational qualifications and skills, practices, knowledge, and preferences within the cultural field. Social capital results from an individual's social obligations and relationships both formal and informal (Bourdieu & Bennett, 2010; Bourdieu & Wacquant, 1992). For example, patients and relatives can activate social capital in the field of rehabilitation by drawing on their formal and informal support networks (e.g. by seeking legal or medical assistance). Economic capital can be activated to purchase private healthcare such as additional physiotherapy or massage.

Bourdieu describes a field as 'a network, or a configuration, of objective relations between positions' (Bourdieu & Wacquant, 1992). In a field some individuals are dominant and some individuals are dominated. A field is a social arena, with dominant social positions, power relations, doxa (a particular perception of reality that dominates in the field at any given time) and struggles (Bourdieu, 2003). The way each individual is positioned in the field is a result of interaction between the specific logic and rules of the field and the individual's habitus and capitals (Bourdieu & Bennett, 2010).

The application of Bourdieusian concepts enables us to describe the forms of capital that individuals draw on in the specific field of rehabilitation after a stroke. We conceptualise the field of rehabilitation as being a subfield of the larger biomedical field, dominated by biomedical interests and expertise in restoring the patient's physical and cognitive functions after a stroke. It is the diagnosis that legitimates the patients' entry to this field.

These concepts from general sociology have been supported by similar inspired concepts developed in the healthcare field. Shim (2010) concept of Cultural Health Capital (CHC) draws on Bourdieu's concept of cultural capital. CHC is defined as: 'The repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviours, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships' (Shim, 2010, p. 1). This concept was developed to understand the social production of unequal treatment in clinical interactions in the US health care system (Shim, 2010). CHC is a specialised form of resource which some patients possess and use to gain advantages.

Integral to CHC is the use of strategy. The practice of strategy consists of competent moves that serve to reproduce one's advantage in the social game (Mérand & Forget,

2013). Individuals' strategies are socially bounded, are activated on an unconscious (habitual) level and are closely tied to his or her social position in the social space, including the individual's capital volume and composition, and not least the experiences and/or habits the body has embedded over time. The concept of strategy refers to dispositions for acting in certain ways or performing, and performing in the right way (Bourdieu, 1992). The concept of strategy must be considered together with concepts of habitus and field, because individuals act on pre-conscious bodily orientation based on habitus to obtain specific services or to improve their position in the field (Bourdieu & Wacquant, 1992), and not to 'lose face'(Goffman, 1972). Thus, in our study Bourdieu's concept of strategy has been used to reconstruct the way patients and relatives maintain or optimise their position in the field of rehabilitation.

Methods

Study design

In order to understand how individuals and/or their relatives participate and experience rehabilitation we designed a study comprising both participant observation of interdisciplinary team meetings followed by semi-structured interviews with patients and/or relatives. The research was undertaken at a specialised stroke rehabilitation unit at a university hospital in Denmark.

Participants

Ten patients with stroke and their close relatives participated. As shown in Table 1, eight out of ten patients had relatives participating in the meetings (wife, husband, siblings, and sons). Five patients had one relative attending, while three patients had more than one relative attending the meetings. In addition to the patient and relatives, between four and six providers participated at each meeting, and a total of 18 different providers were observed during the study. Patients were recruited in collaboration with the charge nurse of the rehabilitation department using purposeful sampling to achieve a broad variation of capital in terms of social position as measured by indicators such as education, profession, and financial circumstances, as well as diversity in gender and age. Patients were referred to the rehabilitation department from the acute stroke unit, which allowed the charge nurse access to the patient's record in advance and made it

Table 1. Characteristics of patients, meetings and interviews.

Patient ID	Gender	Age	Meetings per patient	Relatives per patient	Interview per patient
1	Male	77	3	1	3
2	Female	78	3	1	3
3	Female	54	2	0	2
4	Male	69	4	≥2	4
5	Male	79	6	1	6
6	Female	58	4	≥2	4
7	Female	68	6	1	6
8	Male	52	2	0	2
9	Male	64	2	1	2
10	Male	46	3	≥2	3
			Total meetings 35		Total interview of 35

possible, to some extent, to determine the patients' social position. We included patients with low positions (e.g. manual worker), middle positions (e.g. information specialist), and high positions (e.g. architect and doctor). Patients and relatives were 18 years or older and able to read and understand Danish. Written and verbal information was given before obtaining informed consent to participate in the study.

Data generation

Participant observation

The first author (RG) attended interdisciplinary team meetings that are part of inpatient stroke rehabilitation. These meetings were regarded as key elements of empirical focus because this is where decision-making regarding rehabilitation takes place. The meetings were attended by the patient and relatives along with relevant physicians, nurses, occupational therapists, physiotherapists, and, if required, a speech therapist and neuropsychologist. To capture the balance between being involved in some way while at the same time being in an observing position, the type of participant observation undertaken can be termed 'moderate participation observations' (Spradley, 1980). RG was identifiable to the meeting participants (particularly becoming more familiar to them over time as multiple meetings per patient were attended), but did not actively participate in the meetings.

A theory based observation recording schedule was constructed, with an empirical focus on the interaction between patient/relatives and providers with particular attention paid to how the needs of the participants were met. The meetings were recorded digitally and transcribed verbatim. Field notes were taken. In three cases a clinical specialist nurse took field notes because RG was unable to attend. Thirty-five meetings were observed with between one and six patient/relative dyads present at each. The meetings lasted between 10 and 37 min. The number of meetings was dependent on the patient length of stay (Table 1).

Interviews

RG conducted in-depth individual or dyad interviews with ten patients and/or relatives immediately after, or at least within three days of, the interdisciplinary team meeting. Patients who were cognitively able to participate in interviews decided whether they wished to be interviewed alone or with their relatives. The number of interviews with each patient or dyad varied from two to six depending on the length of stay. Interviews ($n = 35$, lasting 30–60 min) were recorded digitally and transcribed verbatim. A semi-structured interview guide was constructed, based on Bourdieu's concepts, to explore patients' and relatives' experience of decision-making during hospital rehabilitation. The interview guide consisted of two parts. In part one, questions related to the patients upbringing and educational background, past experience with illness and the health system, habitual dispositions on exercise, diet, alcohol, medicine and smoking, economic background and social networks. In part two, questions focused on the current disease and rehabilitation process, examining patients' and relatives' experience of the interaction with the providers and experience with involvement and information.

Data analysis

We performed a qualitative content analysis of our interviews and field notes from participant observation focusing on both manifest and latent content. According to Graneheim

and Lundman (2004) the manifest content is uncovered by analysis of 'what the text says', describing the visible, obvious components of the text. Conversely, the latent content is uncovered by an analysis of 'what the text talks about' dealing with the underlying meaning of the text.

We used the computer software system NVivo version 10 (QSR International) to manage our data. The transcribed interviews and field notes were read several times to get an idea of the visible, obvious components in the text. This enabled deductive coding informed by Bourdieu's concepts of field, habitus, strategy, position and capital. Transcripts were then inductively coded to identify meaning units and emerging categories in the data. The meaning units were then abstracted into four categories. Finally we applied investigator triangulation among the first (RG), second (IP) and last authors (IE, LLM, KL) (Lincoln & Guba, 1985) to reach agreement on the categories and to minimise individual researcher bias or personal preference in the analytic process. The theme, as an expression of the latent content in the text, was developed and discussed among the authors until consensus was reached.

Ethics

The study was approved by the Danish Data Protection Agency (ID 04346), and data were handled according to its requirements, and registered with the Danish Health Research Ethics Committee (ID 17000765). We conducted the study according to the principles of the Declaration of Helsinki, and informed the participants of the voluntary nature of the study and of their right to withdraw at any time with no implications for their further treatment or rehabilitation.

Findings

Our main finding, the deployment of Rehabilitation Capital (RC), and the four categories of Rehabilitation Capital: Performative Participation, Bodily Progression, Institutional Acceptance and Institutional Potential, is interpreted as an empirical specification and extension of CHC (Shim, 2010). From our perspective, RC can serve as a field-specific capital that enables the possessor to leverage advantage in the rehabilitation process. We have defined RC as the resources of an individual or family that are cultivated, valued and traded in the field of rehabilitation, as a physical, behavioural and cognitively embedded attitude and practice.

RC is specific to the field of rehabilitation, relying on attitudes that, individually or collectively, give leverage for benefits and services, such as extra CAT-scans, specialist referrals, group exercises, and extended hospital stay beyond the standardised rehabilitation programme. Patients and relatives are active players in the field of rehabilitation, where progress, motivation, and the will to assist recovery are important factors in obtaining more cooperation with providers and gaining access to more benefits.

To broadly exemplify the phenomenon of this field-specific form of capital, we introduce one of the participants in our study. Paul is in his early fifties, is unmarried and lives alone in a rented apartment. He lacks a social network and his closest relative is his aunt. Paul was born on a small island and moved to mainland Denmark with his parents and four siblings when he was six. His mother worked as an accountant and his father was

an engineer. Throughout his life Paul has dealt with both personal and family related problems. He failed to complete his college education and was unsuccessful in establishing a career: 'I'm not particularly ambitious and never have been, not when it comes to education, job or money, and not regarding family life and such'. Paul suffered depression and eventually retired ten years earlier than expected. His interests ran toward literature and film, and he maintained an active membership in a film club and a whiskey club. Paul was previously fit and able to run marathons, exercising regularly until his stroke. He has been motivated and shows rehabilitation potential despite his modest economic and social capital: 'I believe you have to set high goals for yourself and I feel the need to be challenged; both help my further development'.

The providers regarded Paul as an ideal patient, because of his motivation and progress, giving him the incentive to exercise more and intensify his rehabilitation effort:

> I have done some of the exercises I did with the physiotherapists on the other ward. I have climbed the stairs without holding the banister, I have tried to do exercises standing on my toes on one leg while holding the banister – when I did that last exercise I had trouble keeping my balance.

This quote illustrates how Paul benefited from his determination as a marathon runner as he verbalised his goal-oriented habitus that had built his RC. His RC was converted into additional physical training before hospital discharge. Physical training had a cumulative effect leading to additional rehabilitation that could include more training sessions, a written rehabilitation plan, and the provision of post-discharge communal rehabilitation even when in-hospital providers had deemed this unnecessary. Paul's example shows how his habitus influenced his approach to rehabilitation and how this afforded him advantages in the rehabilitation field.

In the following we will discuss our findings in relation to the four categories of Rehabilitation Capital: Performative Participation, Bodily Progression, Institutional Acceptance and Institutional Potential (Table 2).

Performative participation

Performative participation is the embedded, embodied and cognitive feeling of how to perform in order to be proactive towards own recovery. It comprises two categories (Cognitively Embedded Performance and Self-initiating Activities).

Table 2. Theme, categories and sub-categories.

Main Theme (latent level) Rehabilitation Capital	
Categories (manifest level)	Brief description of sub-categories
Performative Participation	
Cognitively Embedded Performance	The patient's body must perform in a proper manner, being proactive towards their own recovery
Self-initiating Activities	The patients must be self-initiating in the rehabilitation process showing motivation and the ability to self-train
Bodily Progression	Institutional and biomedical expectations of the patient's progress concerning the physiological body
Institutional Acceptance	A set of behavioural components patients must possess to be considered as 'a good' patient
Institutional Potential	An overall rehabilitation potential the patient need to possess in order to recover within the institutionally defined time-frame

Cognitively embedded performance

The ability to perform is a particular type of embodied performance of the physical body, and cognitively embedded performance indicates patients are being proactive towards their own recovery. The ability to perform covers many aspects. It is a way of being proactive, when the patient demonstrates a legitimate attitude towards therapy for example by exercising hard, being determined and goal-oriented, and by accomplishing the rehabilitation goals set for them. Performance was illustrated by communication with providers and participation in goal-setting, when patient and relatives were expected to participate by acknowledging the interdisciplinary mind-set. However, what is legitimate as proactive performance is determined by the providers, rather than the patient. At an interdisciplinary meeting, the son of a patient with stroke suggested that his mother should try to bake a cake. This was not recognised as a legitimate goal, because it fell within the field of occupational therapy alone. The request was not granted although it could have reconnected the patient with her former life.

Performance could be bound to the patient or the relatives. If the patient lacked RC the relatives could participate with their own capital as 'relative-credit'. [We use the term 'credit' as a diminution of capital]. One relative stated during a meeting:

> I have also contributed to [scheduling activities] in the calendar, definitely, so we both speak and write a couple of times a day, while I make sure my mother still gets a bit of rest. (Relative of patient ID 2)

Participant observation also identified situations where the patient failed to perform according to the providers' expectations. One patient, Anne, had not acknowledged her own illness and lacked the necessary insight to cooperate, which also affected her way of using RC. During the meeting Anne neither wished to participate in defining the goals she wanted to achieve, nor in making a plan for how to progress. She also had difficulties in being ready and prepared for the training sessions, and this was viewed as being problematic by the providers. Drawing on other dispositions and values, Anne responded: 'Listen carefully. Staying in bed is the best thing in the whole world'. Because Anne was disinterested she was unable to cooperate, and the providers considered Anne as being challenging. They became impatient and irritated and the focus was on her inactivity instead of the further rehabilitation process. This had the impact that no new goals for rehabilitation were made: 'I am wondering whether we should continue with these old goals? I do not think we should spend much energy on making new goals' (Provider at the meeting with Anne).

Self-initiating activities

Performative Participation also includes Self-initiating Activities as an embodied and cognitive component describing the ability to self-train in an alternative setting to that which applies when training with the providers. The example below illuminates how a patient showed vigour, motivation, and persistency regarding his training. The providers verbally label the patient a 'good' or 'ideal patient' implying the performance of the right actions or describing the right course:

> [Patient] I practice every day. Every day I walk down to the basement, from the fifth floor, to get the paper, and walk all the way up again to get a bit of exercise. Then I try to read a bit of the paper.

[Provider] 'You are an ideal patient'. [Patient] 'I try; I really want to (make progress)' (Patient ID 2).

One way of initiating training is to grab the chance when it is offered: 'I can try to see if I can become number one' (Patient ID 5). Patients are perceived as motivated when they exercise the right way, at the right frequency, and follow the directions of the providers. As an example, a patient states: 'I will follow the plans you make' (Patient ID 5).

Not every patient has the capacity to self-initiate activities. The lack of this capacity is viewed negatively by the providers, although it is a well-known stroke sequela. The quote below illustrates a patient who is incapable of self-initiating. This patient is more difficult to motivate and is perceived as disruptive in the practice of rehabilitation.

> Provider: That is the pattern. We talk a bit about going outside for a little walk, or riding a bicycle or going down to get the paper – but then you say "Of course we can do that, just not right now." It's sort of the same thing. (when discussing Patient ID 7)

The following describes the patient's inability to initiate training from the provider's perspective:

> [Provider]: Yes, so this is the challenge at this point. Sometimes they [patients] get stuck during an activity and have trouble starting a new one. Then they [patients] just sit there … staring at the wall or at people walking by. (Provider at meeting with patient ID 1)

Bodily progression

Rehabilitation progress is bodily embedded. Institutional and biomedical expectations of the patient's progress focus on the physiological body, but illness recovery includes re-establishment of physical and cognitive skills. Rehabilitation progress was measured by goals set for the individual patient by patients, relatives and providers during interdisciplinary meetings and these were mainly related to the progress of the body functions. The perception of goal-setting was different for patients and providers. Some patients were motivated by goals, whereas others found them bothersome. When asked about involvement in goal-setting, one patient said: 'I don't like it much' (Patient ID 5). Then he added what could motivate him in the rehabilitation process: 'Encouragement. I don't believe in that old-fashioned style' (Patient ID 5). The weekly evaluation of goal achievement was a bone of contention between patient and providers: 'When I hear the word "evaluation" … I don't like that word' (Patient ID 5). Patients were uncomfortable being tested: 'I have had my share of exams in my life, so I don't really feel like being examined or tested here.'(Patient ID 5). The providers tried to praise the patients for their hard work and progress:

> [Patient] 'I really think I have improved these last two weeks, but I have also worked hard to get there.' [Provider 1] 'Yes, you put up a good fight.' [Provider 2] 'Yes, you have really worked hard. You have been an ideal patient.'(Patient ID 5).

Institutional acceptance

Initially Institutional Acceptance is about a set of behavioural components a patient must possess to be considered as 'a good patient'. Cooperation with the providers was essential to be considered a good, or an ideal, patient. 'Good patients' had to acknowledge their

disease, strive for rehabilitation progress, and conform to the setting, structure and routines of the institution. A 'good patient' did not ask favours of the providers and did not challenge their knowledge or professionalism by posing critical questions regarding their medicine, tests, or treatment. One patient said: 'I really want to do anything that you suggest, as long as it helps.' (Patient ID 5). Patients and relatives were expected to be proactive, but only to a certain extent and in a certain way. If the attitude was overly proactive the patient did not get credit, but might be excluded from decision-making. One of the wives in our study expected that her husband needed additional tests and medications and kept asking the doctor about her concerns. She said: 'In addition, my husband takes six tablets as a preventive vitamin supplement. He hasn't received them while he's been here, but I think they're important. It's so incredibly important for him to maintain his vision.' (Wife of Patient ID 5). The doctor's response was ill-tempered, trying to interrupt the wife. The doctor failed to enter into a dialogue with the wife and refused to place the suggested orders. This could be explained by the doctor's perception of a meddling wife that questioned his medical decisions.

Institutional potential

Institutional Potential is an 'overall rehabilitation potential' expressed as a professional evaluation of whether or not the 'physical' body actively develops and performs and as such 'participates' in the rehabilitation. Rehabilitation Potential is the physical body's ability to recover within a given time frame, as an example referring to institutional measurements of physical and mental progress (e.g. Functional Independence Measure score and Early Functional Abilities). If the providers assess the patient as possessing such potential, they might initiate goalsetting, longer hospital stay and a rehabilitation plan. This was illustrated when, during an interdisciplinary team meeting, a doctor discussed a severely injured patient with aphasia and cognitive problems:

> Provider: But I think Simon can benefit from training even if he doesn't know where he is […] Good. I think we need to set a new goal for him for the next week and we hope you will have accomplished this when we meet again. (Patient ID 4)

Simon suffered posttraumatic amnesia and the main focus was on regaining his memory. The patient fails to regain his cognitive function during hospitalisation and during meetings his relatives compensate for his loss by providing him with information to keep him calm. The relative has taken part in tasks and training during the patient's rehabilitation.

Patients receive a 'symbolic gift' from the providers when they demonstrate the potential for rehabilitation. As an example, the gift is the right to extend their in-hospital rehabilitation. Conversely patients are discharged sooner if they fail to show physical and mental progress (e.g. as written in the institutional plans). Provider: 'She still has time to train and as there is room for improvement, she stays.' (Provider of Patient ID 2).

Discussion

Our study aimed to examine the capacity of patients and relatives to mobilise resources in decision-making when admitted to a stroke unit. RC offers a theoretical contribution that might help identify and explain the rehabilitation process in relation to patient, relatives

and health professionals, and might thereby contribute to institutional awareness in relation to treatment inequality.

Consistent with Bourdieu's (1992) and Shim's (2010) conceptual frameworks we identified RC as a field-specific form of capital, where those that are able to mobilise RC are advantaged, while those who are not are disadvantaged. Those who possess RC draw on resources that are primarily acquired in the social space (family, friends, and network) and in other social fields (education, workplaces), but can be converted and applied in the field of rehabilitation.

RC has to be considered as a relatively autonomous form of capital within rehabilitation. It is related to the greater field of biomedicine in which autonomy is governed and challenged by economy and politics (Bourdieu & Wacquant, 1992; Larsen & Larsen, 2008). In conjunction with both cultural capital and CHC, RC develops in and through the repeated enactment of health-related practices, such as future-oriented approaches to decision making, dominant biomedical knowledge and goal-setting. This field-specific capital extends the concept of CHC in three ways. First is the particular field within which RC should be considered. CHC was developed after examining private health care clinics in USA, while RC is examined in an even more specific institutional context, namely a public inpatient rehabilitation clinic. RC is also different from CHC in that it is disease-specific. Second, CHC is applied to patients who are able to communicate cultural skills and attributes (Dubbin, Chang, & Shim, 2013), which is not possible in our patient population. Stroke patients are characterised by cognitive deficits, which is why this new form of RC is also bound to the relatives as a family credit. Third, RC captures the institutional framework, policies, structural changes and transformations in the healthcare system. In this way RC and CHC complement each other, but the application and the empirical points of impact differ.

Shim (2010) defines CHC as the kind of activities, resources, and behaviours that carry value in the specific field (Shim, 2010). The same applies for RC that affects the field by supporting the existence of the institution and enable healthcare professionals to set goals and achieve results. By contrast, patients lacking RC challenge the institution by, for example, achieving fewer goals and by longer length of stay. In order to understand the forms of capital that operate within the field of rehabilitation it is necessary to understand the field's particular logic (Bourdieu & Wacquant, 1992). Thus RC is a form of field-specific capital that patients and relatives are able to convert to amenities such as enhancing their position in rehabilitation and obtaining better services. In this situation rehabilitation capital is more potent than economic capital, because money is not the strongest commodity in tax paid rehabilitation in the Nordic welfare states.

Scambler and Newton (2011) have argued that 'previously accumulated capital may be lost, re-evaluated or de-legitimated by the parameters of the fields in which families find themselves' (Scambler & Newton, 2011, p. 131). Similarly we have shown how RC can succeed over other types of capital that lose their value in the specific field of rehabilitation.

While a patient might possess a large amount of capital, the composition of this might not be of significant value in the field of rehabilitation, because the provider refers to a diagnosis based on a standard, without taking into account the patient's embodied dispositions and the positions possessed in other fields and the social space. In this study we examined differentiated practices which contribute to and initiate a discussion about inequality. In the specific institutional context of our study, it was common to give

some patients more attention. We have demonstrated how treatment and care were distributed differently than previously presumed and have suggested a new field-specific form of capital explaining inequality in rehabilitation.

RC is a valuable type of capital in the field of rehabilitation, and, paradoxically, appears as a natural commodity. In our case we have shown that treatment and care is offered within a healthcare system where it is difficult to succeed without the possession of RC. This is particularly unfortunate for people that have suffered a stroke and acquired cognitive and behavioural deficits preventing the accumulation of RC. The issue of inequality is compounded in patients that lack resourceful relatives.

This inequality emerges in the different distribution of professional resources, where the patients who lack RC do not receive the same treatment and care as those who do. The unequal practices are not related to different economic or social resources, as these resources or capitals are somewhat reset in the acute and sub-acute phase during rehabilitation. Crucial to receiving special treatment and care is therefore whether the patient undergoing rehabilitation is able to perform well or not. It is important to stress that the individual providers are not a product of a deliberate strategic intention to increase inequality in rehabilitation. The providers are part of a larger institutional and professional doxa that is governed by a range of requirements that are out of their hands (Retsinformation, 2012).

We examined how patients and relatives deal with in-hospital rehabilitation and have presented and discussed the different strategies used by patients with varying backgrounds and resources. We have found, similar to Bourdieu's (1992) concept of strategy and Shim's (2010) theory of CHC, that RC is mobilised and invested by unintentional, habitual schemes of perception and action that are embodied thought experience and that influence the rehabilitation process. Individuals are socially and culturally heterogeneous with varying values (Latimer & Skeggs, 2011; Skeggs, 2011), but the most patients wish to perform well and achieve the goals set jointly by patient and provider. Similarly Wiles, Ashburn, Payne, and Murphy (2002) illustrated that it is of great importance for the patients' achievement of complete recovery to be encouraged by the physiotherapists, suggesting that the importance of encouragement might be applicable or transferable to all types of providers (Wiles et al., 2002). As such, patients try to exhibit the qualities they expect the providers to value. Complying with the providers ultimately influences positively on the patients, because they perform even better when they experience praise, encouragement and reward. Patients that are unable to comply, for different reasons, receive only standard treatment as they are unable to capitalise on their RC. Providers of rehabilitation need to be aware of the unintentional failure to adhere with their expectations by patients that are incapacitated by stroke and other diseases. RC is a resourceful and relational form of capital, and its absence is significant on an existential level for both patients and relatives.

Strengths and limitations

One of the strengths of this study was the ability to capture the experiences over time of both the patients and their relatives. All participants were followed from admission to discharge which means there were no dropouts. To ensure credibility and to illustrate a wide range of diverse capacity of patients and relatives (Graneheim & Lundman, 2004), the

patients in our study represented a wide range of cultural, economic and social capital. The combination of field observations and individual semi-structured interviews provided insight into the perspectives of both patient and relatives. In addition, investigator triangulation increased the confirmability of the study (Graneheim & Lundman, 2004). Our study was limited by being a single-centre investigation, decreasing the transferability of our findings. Further research focus upon identifying RC and how it works, may improve the providers' awareness of the mechanism of inequality in rehabilitation.

Conclusion

RC adds a new theoretical component to explain certain dimensions of the interaction between patient, relatives and providers in the field of rehabilitation, at the micro-level and on the organisational level. It increases understanding of current rehabilitation practices and helps to suggest improvements in clinical practice and patient involvement. In the specific field of rehabilitation the capital that is useful in giving patients an advantage needs to be specific to the field (Scambler & Newton, 2011). We have presented a field specific capital at work in rehabilitation, even within the welfare state. As presented, social inequality is seen in the distribution of illness, access to the healthcare system, treatment, and the overall rehabilitation process. Patients and relatives possessing rehabilitation capital are better prepared to adjust to the 'rules of the game', thus potentially accessing benefits and services not available without RC. As such, we regard RC as an additional resource potentially benefitting patients and relatives during inpatient rehabilitation. This form of field-specific capital facilitates more attention from healthcare professionals and benefits the rehabilitation process in general.

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Appendix B Paper II

Title: Manuscript Title: Relatives´ strategies in sub-acute brain injury rehabilitation: the warrior, the observer and the hesitant

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MAIN DOCUMENT

Manuscript Title: Relatives´ strategies in sub-acute brain injury rehabilitation: the warrior, the observer and the hesitant

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DECLARATION OF INTEREST

The authors have no conflict of interest to declare.

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Abstract:

Background: Relative involvement is crucial in rehabilitation when patients are incapable of being involved due to cognitive and functional dysfunction. However studies have shown that this is complex because of differing understandings of the meaning of involvement as well as diverse needs to be involved.

Aims and objective: We explored the experience of the rehabilitation process from the perspectives of relatives of patients with a traumatic brain injury. The aim of the study was, through a theoretical-empirical analysis, to identify relatives' strategies and practices in the rehabilitation process as evidenced in meetings with providers.

Design: A longitudinal study with a qualitative approach, drawing on the theory of Pierre Bourdieu. **Methods:** Data were generated using participant observation and semi-structured interviews. Participants were eleven relatives of patients with a severe traumatic brain injury, followed through in-patient rehabilitation varying from nine to twelve weeks. Analysis was undertaken using both an inductive and deductive approach.

Findings: Drawing on Bourdieu's concept of strategy, three relative positions were identified, the warrior, the observer and the hesitant. These positions illustrate how different relative positions and their related dispositions influence the strategies used by relatives of patients with a severe traumatic brain injury evidenced in how they act, participate and relate to both the patient and the providers during the course of rehabilitation.

Conclusions: Acknowledging the relatives' positions during the rehabilitation process enables better understanding and support of the relatives in the rehabilitation process in order to meet their (and thus the patients') diverse needs.

Relevance to clinical practice: The findings have practice implications in informing how clinicians meet, interact, communicate, and involve relatives of adult patients' with traumatic brain injury in decision-making during rehabilitation.

Keywords: Bourdieu, Decision-making, Interdisciplinary team, Qualitative research, Rehabilitation, Relatives, Traumatic Brain Injury.

INTRODUCTION AND BACKGROUND

Traumatic brain injury (TBI) is a major health concern throughout the world (Roozenbeek et al., 2013; Maas et al., 2008; Sundstrøm et al., 2005) causing death and disability (World Health Organization, 2009). Patients with a severe TBI are admitted to an intensive care unit and, if they survive, often have severe physical impairments and disabilities as well as

behavioral, social and cognitive sequelae, which require long-term rehabilitation (Benedictus et al., 2010). These impairments affect the patient's participation in the decision-making process during the admission to a rehabilitation department and relatives become important participants as a proxy to advocate for patients (Doser & Norup, 2016). In Denmark, as in other countries shared decision making is integral to a patient centered care approach and there is political emphasis on increasing involvement of patients as well as relatives (Ministeriet for Sundhed og Forebyggelse (The Ministry of Health), 2014; Videnscenter for Brugerinddragelse i Sundhedsvæsenet (The Danish Knowledge Center for User Involvement in Health Care), 2014, 2015). Research has found that relatives' involvement is linked to better rehabilitation outcomes for individuals with a TBI (Foster et al., 2012).

Relative participation in rehabilitation could be understood as involvement of the relatives as a resource in the patient's course of disease which is particularly important if the patient is not conscious, as in many patients with a TBI. It could also be understood as actively involving patients and relatives in goal-setting: Defining their wishes, making an action plan to achieve their goal, and making decisions about their own care (Leach et al., 2010; Holliday et al., 2007). However, there are challenges in the way patients, relatives and healthcare providers (hereafter called providers) grasp what involvement means and the implications of being involved. While specialized in-patient rehabilitation providers are used to working with patients with severe TBI, families are not. They do not have formal training and support to care for persons with severe TBI (Ramkumar & Elliott, 2010). The new situation can be very stressful and overwhelming. Little knowledge, however, exists about the experiences of families and individuals with TBI in the rehabilitation process. A Swedish study conducted by Jumisko et al. (2007) themed 'being excluded', highlighted how patients and relatives felt avoided by staff, and had a sense of being ruled by authority (Jumisko et al., 2007). Their experiences of exclusion also included patients' and relatives´ unmet

informational and emotional needs. A range of studies support the evidence that relative and patients have unmet informational and emotional needs during the inpatient rehabilitation process (Keenan & Joseph, 2010; Bond et al., 2003; Mirr, 1991; Lefebvre & Levert, 2012). Bond et al's study highlights how relatives need to make sense of the traumatic experience, and how they take on a caregiving role, wanting to be involved in the care in the initial stage of rehabilitation (Bond et al., 2003). Problems being involved are expressed by relatives as a feeling of being 'in the way' of the health care professionals (Bond et al., 2003). From another perspective, a Norwegian study examining caregiver burden and quality of life found that 30% of family members of patients with severe TBI reported an increased caregiver burden, one and two year post-injury (Manskow et al., 2017). Knowing that increased caregiver burden might have a negative impact on the person with severe TBI, Manskow et.al (2017) suggested that more tailored follow-up of patients and family members is needed with a focus on professional support to relieve burden (Manskow et al., 2017).

While previous studies show that relatives of patients with TBI are important participants during the patients' rehabilitation process, relatives express different needs for information and support, as well as different opportunities and wishes of being involved in the rehabilitation process. It is therefore important for both practice and research to explore how to differentiate relatives and their different ways of interacting in neurorehabilitation and especially how this can be tied to their earlier experiences, resource and competences. Such knowledge can be used to identify the range and diversity in needs for involvement, information and support.

Theoretical approach

To examine the experiences of relatives in rehabilitation, we focused on their beliefs and practices, their capacity to mobilise resources, as well as how they were able to situate themselves in the processes of field of rehabilitation specifically and the healthcare system

generally. Bourdieu's conceptual triad of habitus, capital and field enable consideration of relatives' prior assumptions, beliefs and experiences (habitus), the material or symbolic resources that can be leveraged in encounters in healthcare (capital), and the context of rehabilitation itself (the field), all of which will shape their capacity to achieve the outcomes that they desire (Collyer et al., 2015). Bourdieu's related concept of disposition is used to analyse different relatives' diverse capital volume and composition of capitals and how this influences their decision-making in the rehabilitation process, because these predispose, but do not predetermine how individuals act in everyday life. The concept of positions enables exploration of how these dispositions perform in the field of rehabilitation. Bourdieu's theories are applied worldwide in different fields and the extra value of the theories are the epistemological breaks with everyday constructions often associated with e.g. psychological, individualistic, cognitivist or moral concepts (Bourdieu et al., 1991). Thus, social and bodily practice are located and understood not only as interaction in organizations, but as different practices in different social fields (e.g., like persons are acting in a bank, at a festival or in a medical field). Thus, analytically Bourdieu's concepts help to provide insight into differently positioned relatives' strategies. Lastly Bourdieu's theory adds to other theories on how relations of dominance work on both micro, meso and macrolevel, e.g. how differently positioned relatives are more or less confident in the field depending on different amount and compositions of capital.

To our knowledge, no earlier studies map different positions and dispositions relatives of individuals with a severe TBI possess. We assume that it is possible to map some classifications, because patients and relatives behave differently based on demographic information like social class, gender, age, the ability to cope and eventually also by factors such as the aetiology of the trauma etc. (Bourdieu & Bennett, 2010). If it is possible to identify different positions and dispositions possessed by relatives of individuals with a

severe TBI, it would be possible to differentiate their needs for support and information from the health care providers. This would potentially benefit both patients and relatives.

The aim of this study was to undertake theoretical-empirical analysis of relatives' strategies and practices in the rehabilitation process as evident in meetings with providers. We explored the experience of the rehabilitation process from the perspectives of relatives of patients with a TBI. Our research question was 'what kind of strategies do relatives of patients with a TBI apply and use in the rehabilitation process?'.

METHODS

As outlined above, key concepts from Bourdieu's conceptual triad of capital, field and habitus and the concept of strategy guided the study's research questions, methodological choices, the construction of the interview guide, and techniques to work with the empirical data (Bourdieu & Bennett, 2010; Bourdieu & Accardo, 1999).

Design

We designed a longitudinal study comprising participant observations of interdisciplinary meetings (meetings) followed by qualitative semi-structured interviews.

Setting

The study was conducted in a sub-acute 22 bed highly specialised rehabilitation department for patients with severe TBI at a university hospital in Denmark from November 2016 to September 2017. The department is one of two centralized departments in Denmark.
The observations were undertaken during the meetings which are considered as key elements of empirical focus because this is where decision-making regarding rehabilitation takes place. The purpose of the meetings was to discuss the clinical assessment of the patient and the patient's likely prognosis, length of stay and later in the rehabilitation process, also the discharge destination. In the meetings attended the patients´ relatives, the members of the patient's interdisciplinary team; nurse, neurological consultant, physiotherapist, occupational therapist, neuropsychologist and speech-lingual pathologists when relevant. The first meeting

was on the day of the patient's admission at the clinic and the relatives were informed at the neuro intensive unit that a meeting would take place and that their participation was expected. The meetings were followed up every three weeks until discharge.

Participants

The participants were eleven relatives of nine patients with severe TBI with impaired consciousness at admission to sub-acute rehabilitation in the states of unresponsive wakefulness syndrome (UWS), minimally conscious state (MCS) or posttraumatic confusional state (Laureys et al., 2010; Katz et al., 2009). Therefore patients were not cognitively able to participate, neither in the interdisciplinary status and planning meeting (hereafter called meeting) nor in being interviewed. There was a majority of male patients, probably because they are in a high-risk group of being involved in motor vehicle accidents, violence and work related accidents (Roozenbeek et al., 2013; Maas et al., 2008) (Table 1). Participating relatives were recruited in collaboration with the interdisciplinary management group of the rehabilitation department using purposeful sampling (Polit & Beck, 2014) to achieve a broad variation of participants in terms of social position in education, profession, and financial circumstances. We included relatives from the working class, positioned in low positioned jobs (e.g. a cleaner), relatives from middle class positions (e.g. a bank employee), and relatives in high positions (e.g. executive positions). The participants had varying age and relationship with the patient (Table 1). Participating relatives were 18 years or older and able to read and understand Danish. Patients were also 18 years or older.

Data Collection

Observations

Moderate participation observations as defined by Spradley (1980) were undertaken by the first author, meaning that the researcher was identifiable to the participants, (particularly becoming more familiar to them over time as multiple meetings per patient were attended) but did not actively participate in the meetings. The first author was present in the clinic approximately 30 minutes before and after the meetings, doing observation of the relative's interactions. A theory based observation recording schedule was constructed, focusing on the interactions between relatives and the providers with particular attention to how the participants were involved. Field notes were taken during and after the meetings. Twenty-two meetings were observed. The meetings were scheduled for 30 minutes and lasted between 20 and 46 minutes.

Interviews

In order to capture the participants´ habitual dispositions and their experiences of the rehabilitation process, in-depth individual interviews with eleven relatives immediately after, or within three days of meeting by the first author. A semi-structured interview guide was constructed, based on Bourdieu's concepts, to explore patients' and relatives' experience of the interaction with the providers, experience with their own involvement and information as well as decision-making during in-hospital rehabilitation. The interview guide consisted of two parts. Part one was used at the initial meeting and the questions were related to the patients' and relatives' upbringing and educational background, past experience with illness and the health care system, habitual dispositions on exercise, eating, alcohol, medicine and smoking, economic background and social network. Part two was used at the following meetings and at discharge and the questions focused on the rehabilitation process, examining patient and relatives' experience of the interaction with the providers and experience with

involvement and information. As an example one relative was asked: 'I noticed that you are writing a lot of things in your notebook during the meeting. Do you mind telling me what you are noting down and why?' Examples of the topics from the semi-structured interview guide have been provided in table 2.

The number of interviews with each relative varied from two to three depending on the length of the admission. Interviews (n=23, lasting 23-140 min) were recorded digitally and transcribed verbatim. In one case both parents of a patient participated together in the interviews, supplementing and supporting each other (relative ID 7). In another case a parent couple both wanted to participate in the study, but were interviewed separately as they did not wish to be interviewed together (relative ID 9a+b).

Analysis of observations and interviews

Analysis of interviews and field notes was undertaken using both an inductive and deductive approach using a computer assisted analysis: QSR International NVivo version 10. In the following, the process of analysis is described as if it was a linear process, but the analysis was a back and forth movement between the two approaches.

Inductive Phase of the analysis

A qualitative content analysis was undertaken of both observations and interviews (Graneheim & Lundman, 2004). This analytical approach aims to identify and accept multiple meanings, focusing on the manifest content in the data. The analysis followed the procedure suggested by Graneheim and Lundman (2004). First, the transcribed interviews and field notes were read though several times to get an idea of the visible, obvious components in the text. Second, important word, sentences and/or repeated contents were marked and noted and meaningful units of the texts were identified, which enabled identification of the visible, obvious component or manifest content in the data. Third,

meaningful units in the text, were abstracted into four categories: Bodily and verbal interaction, Relation with the providers, Perception of own involvement and Perception of the patient's illness (Graneheim & Lundman, 2004).

Deductive phase of the analysis

In the deductive phase of the analysis, the concept of strategy, disposition and position was applied to the empirical data to provide a relational and a dynamic approach to the analysis, as well as enabling us to construct the different positions of the relatives and their strategies. The Bourdieusian concept of disposition was used to analyse relatives' diverse capital volume and composition of capitals and how this influenced their decision-making in the rehabilitation process. The concept of positions was used to explore how these dispositions performed in the field of rehabilitation. It formed some underlying/fundamental assumptions about the participants embodied experiences (dispositions and habitus). The constructed types are a theoretical construction, where the characteristic which is assumed to be substantial in order to map the different relatives thinking, acting and life course was selected. The identified categories were entered into a descriptive matrix (Averill, 2002; Miles et al., 2014) to facilitate the examination of how relatives´ diverse strategies intersected with each category. An example, from the category 'relatives relation to the patients illness' has been provided in table 3. According to Miles & Huberman (1994), a descriptive matrix in qualitative analysis, involves 'the crossing of two or more main dimensions . . . to see how they interact' (Miles et al., 2014, p. 239).

Ethics

This study received approval from the Danish Data Protection Agency (ID 04346), and data were handled according to its requirements, and registered with the Danish National Committee on Health Research Ethics (ID 17000765). The study was conducted according to

the principles of the Declaration of Helsinki. Written and verbal information was given before obtaining informed consent to participate in the study. Participants were informed of the voluntary nature of the study and that withdrawal from the study was possible at any time with no implications for future treatment or rehabilitation. Pseudonymns are used when reporting findings.

FINDINGS

Three different positions among the relatives in rehabilitation were evident: the warrior, the observant and the hesitant. The warriors are characterised as being proactive and fully engaged in decisions about care, and directing the processes to maximize the benefit for their relative. The observers are collaborative with, and helpful to, providers and are concerned to do whatever providers direct as being in the best interests of their relative. The hesitants are characterized as being primarily reactive to the decision making processes and uncertain of their role.

While these relative positions are presented as if relatives occupy only one position this is not the case in practice. The relatives fluctuate between the positions depending on both the patient's condition and progression, and their growing expertise with the rehabilitation field. However, the initial interactions with the providers, habitus and capital influence the roles that are played and their related dispositions influence various strategies used. These initial positions are evident in how relatives act, participate and relate to both the patient and the providers during the course of rehabilitation, just as the relatives ability to adjust to the field-specific rules that are internalized in the rehabilitation institution ('the rules of the game'). It seems that the cultural preferences are differently distributed among these different positions and this influences the strategies able to be adopted. For example, it became evident in the initial interviews that the warrior tends to occupy more privileged positions in society, based on education, cultural capital (e.g. holds relatively high

to medium high economic capital) and cultural preferences for example distinctive preferences in terms of food, beverages, shopping malls. The observer tends to occupy moderately privileged positions in society (e.g. self-employed work or permanent employment in small private enterprise) and cultural preferences for example distinctive preferences in movies, literature and theater. The hesitant, on the other hand, seems to occupy moderate to less privileged positions in society (e.g. unskilled work) and cultural preferences go towards, for example, distinctive preferences in reading, television series and food.

The three positions were constructed by centering on the following four categories that emerged from the data: Bodily and verbal interaction, Relation with the providers, Perception of own involvement and Perception of the patient's illness.

Bodily and verbal interaction

In the category termed bodily and verbal interaction relatives presented themselves differently in the meetings both bodily and verbally, which was evident in their capacity to use cultural and social capital as a strategy in the rehabilitation process.

During the meetings the warrior bodily appearance is prepared, sitting in the front of the chair often with the arms resting on the table, often with a paper and pen. The warrior mostly has good eye contact with the professional and exhibits non-verbal communication (e.g. leaning back in the chair and folding arms across one's chest if they do not agree with the providers). The warrior is present in the department most of the day and evening hours, so the meeting is part of their engagement in the department. The warrior attends the meetings with one or more other members of the close family.

During the meetings the warrior was keen to share their own observations about the patient, for example, relative ID 5 indicated the importance of this at interview:

> 'I was absolutely sure that behind the filter, he was present. And there was none of the staff seeing it. So that part I felt was totally frustrating and I felt like I should fight for his rights. I think I should fight and tell them what I was observing looking through the filter that they did not see' (relative ID 5).

This indicates that the warrior are aware that their observations is important for the further rehabilitation process and that they find that health professionals do not always observe the same progress that they do. The warrior asks many questions of the providers during the meetings indicative of confidence from middle or higher education (medium to high cultural capital) and therefore the capacity to leverage their cultural capital into dialogue with the providers.

Similar to the warrior, the observer appears prepared during the meetings and asks clarifying questions of the providers. During the meetings the observer is interested in the providers' professional view on practical issues such as: numbers of visitors, visiting hours and coordinating visitors, as well as more existential questions as rehabilitation outcome, length of stay and economic issues. During the meetings, the observer primarily is concerned with practical conditions such as duration of hospitalization, visit times and coordination of these visits.

Contrary to the warrior and to a lesser extent the observer, both of whom appear familiar with the meetings, the hesitant wears outdoor clothes, suggestive of a visitor in the room. The hesitant is seated back in the chair with arms crossed and does not seek eye contact with the providers. The hesitant often leaves the department immediately afterwards the meetings. The hesitant is engaged in the meetings to hear the providers provide information about the patient's progress, primarily with regard to physical functions. They also express concern

about the future: ‘I think about when he gets better and if he will ever become normal and what we will do in the future’ (relative ID 4).

Relationship with the providers

The relatives’ relationship with the providers during the course of rehabilitation varied across the three positions, both in the expectations of who should provide information, as well as the way they were able to communicate and cooperate with and relate to the providers. This appeared to be related to the relatives’ different levels of capital, particularly cultural capital, which shaped the relatives´ ability to effectively navigate the rehabilitation process and the interactions with the providers. Cultural capital was important in shaping the different experiences of the relationship with the providers.

The warrior´s relationship to the providers is, to a great extent, based on dialogue. Warriors perceive a great need to receive information from the providers, especially from the physician who was viewed as the most reliable source of information. The warrior prefers daily contact with the physicians, particularly in the beginning of the admission. The warrior critically refers to who gives information. The following example illustrates this point:

> ‘It is very important that you do not get different information, diverse information. And from whom you get information from. It is not inconsequential from whom you get it. It should not be the lowest-ranking nurse. You need to be informed by the responsible, competent doctor or nurse’ (relative ID 9b).

The warrior requires extra meetings with the consultant and is able to achieve this multiple times during the hospitalization, even when such meetings are outside the standardized rehabilitation process.

The warrior is aware that they interfere with the established order and/or balance of power, but is also aware of the boundaries of their behavior. For example, relative ID 7 said: 'You must behave properly, that is, if you are not empathetic or people do not like you, then you can act as badly as you possibly do, you're just tripping yourself' (relative ID 7). The warrior can appear demanding, critical and/or challenging: 'Sometimes I've known a bit better, I really have' (relative ID 3). They often consider themselves to be the expert to judge the quality of care and treatment. In contrast to the hesitant and the observer, the warrior has capacity to leverage their cultural capital in their interactions with providers. While they may not master the specific biomedical language, classifications and logic, they can convert cultural capital to acquire the dominant language, attitudes and preferences. 'I have some strategies that I use in my daily professional life which I can also use in this room' (relative ID 7).

The observer considers the providers as collaborative partners, where the observer cooperates with the providers for the benefit of the patient. The observer wishes for greater access to information, like a weekly meeting rather than the monthly progress meeting, but does not voice this need. Thus, the observer´s relation to the providers is characterized by solidarity and loyalty. The observer will voice concerns, but will wait until staff are available, rather than demand immediate resolution. This is indicated by relative ID2 who states: 'Although I know that there is a lot of staff, there are also many patients and there are many that are complex, so we do not always see anyone. But then, if we have a question, we will wait until someone (provider) appears' (relative ID 2).

The hesitants' relation to the providers is on the other hand characterized by one-way communication and humility to the expertise, trusting that the providers are well equipped to manage the patient's care. It is the providers who are considered experts in the

field of rehabilitation, and the observer does not ask question or raise critical issues about treatment and decision making. While the hesitant may express the need for more information; they are uncertain of actions to obtain it and therefore seems to be a passive recipient of information. The hesitant does not acquaint themselves with the specific course of the disease, and puts trust and faith in the rehabilitation team's treatment choices. 'I don´t ask a lot of questions. I just don´t' (relative ID 1). In other words the hesitant relates and responds passively to the health professionals. Because the hesitant has generally low to moderate economic and cultural capital, they primarily perform with the hands and not verbally or intellectually, and thus have less capacity to engage in dialogue with the providers. The hesitant 'melts into the wallpaper' when visiting and asks none or only very few questions of the providers. The hesitant considers they are a visitor to the rehabilitation unit and neither receives or gets care tasks nor undertakes care and/or treatment tasks from the providers.

Perception of own involvement

The three relative positions had differing perceptions of their own involvement, in terms of how to act and participate in the rehabilitation process. This can partially be attributed to their opportunities to deploy cultural capital and economic capital, for example having flexibility from the place of employment is of great importance in enabling attendance at the progress meetings.

The warrior draws on their own role and activity, such as attorneys, lawyer, guardian, extended arm, coordinator and instrument, and considers themselves as partners with the providers in the decision making processes. The warrior acts as a quasi-professional and is present during the entire hospitalization process. Warriors have the capacity to spend many hours every day in the department indicative of a work situation with maximum

flexibility to enable such a response. ‘I have been there day and night. I think I've been there between 12 and 18 hours, every day for 80 days’ (relative ID 3).

The warrior is involved with care, thus developing a whole range of specialist skills and knowledge during the rehabilitation process e.g. being legitimized to administer medication. Furthermore the warrior is able to appropriate and apply field specific languages and rules. For example, they learn how to cooperate with the nurses in a way that displays competence but does not overstep nurses’ professional qualifications. For example, a relative (father) explained how he over time had built up confidences with the nurses, so he was allowed to deactivate the equipment that measured the oxygen level in the blood, without consulting them (relative ID 7).

The warrior is active and dynamic and does not always agree with the professionals’ assessments and decision making. To some extent, the warrior is able to adjust ‘the rules of the game’, questioning the rules by taking action, potentially accessing more benefits and services from the providers. As an example a cohabiting male was dissatisfied with a decision made by a nurse concerning a drainage tube: ‘Then I simply went out and found the doctor. I knew all the neurosurgeons and most of the nurses and all anesthetists and everybody in fact. So I went in and got it all started’ (relative ID 3).At the same time the warrior considers himself as an ideal relative, particularly where he can supply resources that are articulated by the professionals as needed. ‘You're almost working as a therapist, it's really cool’ (relative ID 3).

In contrast to the warrior, the observer must adjust to ‘the rules of the game’. This occurs by observing and assessing, not questioning the information the providers give during the progress meetings as well as the providers’ actions during their daily visits to the department. ‘I observe a lot but I know that he is in good hands’ (relative ID 8). Observers only take action if necessary but behave otherwise neutrally. The observer experiences their

own role as being in a challenging balance between other roles and responsibilities. For example, the observer experience being in a conflict balancing family life, work and visiting the patient at the hospital. This has the consequence that the observer constantly feel guilty about not being able to be enough either at home, at work or at the hospital, and is indicative of less flexibility from the workplace and in their other roles.

A different perception of 'own involvement' is demonstrated by the hesitant, who possesses a wait-and-see attitude. The hesitant is a layperson that does not pay attention to themselves and appears silent, avoiding conflict and having faith in authority to a certain limit. 'We take one day at a time' (relative ID 1). But there are also examples showing that if the hesitant experiences his/herself as unfairly treated, this becomes explicit to the providers. As an example one sister explained how she felt in an interaction with a physician, frustration over not getting a promised meeting: 'We felt so bad. As if it was the family they had been pushing for a meeting, it was actually initiated by another doctor. It feels like one hand does not know what the other hand is doing' (relative ID 1). She explained how she expressed her dissatisfaction at not getting the meeting. In this way it appears that the hesitant is able to talk back to the providers, if they feel their boundaries are crossed, but is not part of their usual disposition to give words to their frustration to others positioned above themselves.

The hesitant experience minimal flexibility from their workplace, which means that the hesitant needs to prioritize their work, rather than being at the hospital. As a consequence, the hesitant visits the hospital for 1-2 hours a day, 2-3 times a week, and calls in daily for the patient's condition. Visits are most often in the evenings, where there are not so many providers present. The hesitant, rarely asks for the providers help since they does not want to inconvenience the providers. 'I feel like it's only if I really need help I will to ask for it' (relative ID 8).

Perception of the patients' illness

Relatives' positions also differed concerning perceptions of the patients' illness and interpretation and ascription of value regarding potential disabilities.

For the warrior the mental and cognitive aspects of the illness were most important, and indicative of valuing the cognitive capacities above others. 'It does not matter if there is increased function of the arms and legs as long his intellect is preserved' (relative ID 5). The warrior participates actively in training and ward rounds where they are part of a professional back-and-forth interaction with the providers. The warrior's strategy is to obtain the most achievable, lengthy and most effective rehabilitation, as possible. 'If that is the best place, then we have to bring him there, even if it was on the moon' (relative ID 7).

Similar to the warrior, the observer highlights the mental and cognitive capacities, and only has little concern about the physical disability that might remain after the rehabilitation process. 'I am not afraid to get Peter home in a wheelchair. Handling a wheelchair will not be a problem for me. As long as Peter can use his arms, his mental functions and his language, so we are able to communicate' (relative ID 8). The observer participates in training and during ward round if they happen to be present in the department rather than participation being an active choice.

In contrast to the warrior and the observer, the hesitant is concerned about the physical disability, rather than the mental and cognitive disability, which means that they are more inclined towards the functional and physical body. 'Well, it does not matter if you forget things once in a while. That's the least. As long as he does not have pain and will be able to walk again' (relative ID 6). The hesitant does not participate, or rarely participates, during the training sessions or during ward rounds and therefore appears to be passive regarding involvement in care and treatment. The hesitant's stance towards rehabilitation is

that rehabilitation should take place as close to home as possible, although it is not necessarily the best facility, according to the providers professional assessment.

DISCUSSION

The main finding of our study was the identification of three different relatives' positions in sub-acute neurorehabilitation determined by the individual's habitual dispositions, which provides a set of underlying dispositions indicating how the relatives are able to navigate through the rehabilitation process.

By analyzing how relatives bodily and verbally interact, how they relate to the providers, how they perceive own involvement and how they perceive the patients' illness the generative themes and strategies of the relatives (e.g. perception, thinking, feeling, evaluating, speaking and acting) become evident. This is, for example, reflected in the warrior who develops knowledge and skills during the rehabilitation process, (e.g. engaging in medical preparations and administering medicine) as well as acquiring 'rehabilitation language' and the field-specific rules. The Bourdieusian concept 'hexis' (bodily element) enables us to reconstruct a mode of practices, as part of one's habitus, that will appear (expressive, verbal and practical) in different empirical areas. So for example an individual who possesses language-using practices, being proactive, active and inquiring will have a tendency to always act the same way in similar situations and will often bear the same features (bodies, apparel, posture), in the bank (economic field), in the private life, in the bringing up of children as well as in health care field. When the types of habitual dispositions are acquired is it possible for the language user to improvise and produce linguistic expressions that are not only grammatically correct but also suitable for particular situations. It can be expressed as a capacity to produce appropriate terms 'apropos' i.e. convenient and timely (Bourdieu 1991, p. 7). But it could also involve a capacity to be heard, believed, and

trusted and perhaps even obeyed particularly if there is a reception from the dominating actors within the specific field (Bourdieu & Wacquant, 1992).

The relative positions we have identified are theoretical constructs that are not directly applicable to label concrete persons or social groups. The positions in rehabilitation are not meant to categorise relatives as being 'good relatives' or 'bad relatives', 'difficult relatives' or 'easy relatives'. In addition the relative positions are not meant to be used only in a descriptive and functional manner. It needs to be understood in a dynamic sense and fundamentally as a framework to think with. According to the sociologist Max Weber (1968) an ideal type is formed from characteristics and elements of the given phenomenon, but it is not meant to correspond to all of the characteristics of any one particular case (Weber, 1968). Thus, every relative will have minor or major fragments of the characteristics of the three positions, but the positions should cover possible discrepancies in the observed field of practices. Thus, these ideal types are not meant to correspond to all of the of any one particular case. Relatives' positions enable us to think, prepare and try to understand the relative's diverse way of acting in-patient rehabilitation and not a normative category. It is an attempt to extend the 'types' of relatives beyond patients stereotyped by providers.

A key finding was that the warrior, observer and hesitant showed diverse needs for information and support during the rehabilitation process. If the providers are aware of the differences between relatives they could provide are more equal treatment and care in the rehabilitation process. Providers should be able to accommodate different individuals, and in order to do this, providers must treat relatives from their point of view and not the providers' point of view. The need to individualize information and support for patient' and relatives' parallels previous research. For example Lefebvre and Levert (2012) examined the needs of people close to individuals with a TBI, from the point of view of the individuals with a TBI and providers. Similar to our study, Lefebvre and Levert fund that whatever information

relatives do receive must correspond to their individual needs here and now, both in terms of content and quantity and preferable coming from few sources (Lefebvre & Levert, 2012). Sekse (2012) identified three typologies in a qualitative study, describing how the women, in different ways, negotiate living through cancer illness (Sekse et al., 2012). In line with this current study Sekse et.al (2012) concluded that there in cancer care is a need to create a follow-up process that is individually tailored for each patient.

Another finding was the different relatives' positions diverse need of being involved in the rehabilitation process. As our findings suggest, patients and relatives have different starting points (dispositions and habitus) and thus different possibilities and needs for being involved in the rehabilitation process are expressed. It is therefore important to consider relatives habitual dispositions, in order to determine the relatives' influences and desires about being involved as well as their decision-making capacity, when involving them in the decision-making process.

It is evidenced in the literature that active involvement of relatives is a key element in successful rehabilitation, yet very complex. As suggested by Fisher et.al. (2017) relatives should be acknowledged and utilized in the decision making process and relatives and providers should work collaboratively together to maximize rehabilitation outcomes (Fisher et al., 2017). This is in line with findings by Kuipers (2014) stating that relatives must be engaged more effectively in the rehabilitation process (Kuipers et al., 2014). However, it would appear of great importance to include relatives' habitual dispositions, as their habitual dispositions determine different forces to be involved as well as decision-making capacity, when being involved in the decision-making process. While a recent study has focused on how to increase family involvement by developing a theoretical model to increase family

involvement for individuals with brain injury (Fisher et al., 2017), other studies have examined the barriers of involving patients and relatives. From the perspective of the providers Levack (2009) illustrated how barriers of involving family members in goal-setting were perceived as related to the family' unrealistic objectives for rehabilitation and timeframe for recovery and was thought not always to be in the best interests of the patient (Levack et al., 2009). In a study conducted by Asimakopoulou et. al. barriers in involving patients, were linked to difficulties with overly engaged patients (asked to many questions, came with so much questions, came with too much information, were to demanding and took up to much time) or less keen patients not interested in joining in with decision-making (Asimakopoulou et al., 2014). What these studies miss are to take into account the meaning of the individuals' habitual dispositions and the different strategies they apply as a consequence of that. If the providers do not know the relatives starting point, it seems difficult to individualize and tailor the specific need for involvement of the relatives, which suggest that the interdisciplinary team of providers should be offered information and education about the different relative positions strategies, in order to match the relatives' different need for being involved.

Strengths and limitations

Complementing observations with semi-structured individual interviews enables the gathering of perspective that might otherwise be missing in rehabilitation, particularly because the voice of an individual with a severe TBI may be hard to hear otherwise. The use of Bourdieus´conceptual framework enables deepening of our understanding of the strategies applied by relatives in a nuanced way and it is seems apparent that if this framework is productive in relation to this, it is likely to be of relevance also to a wider range of other long-term conditions afflicting patients and relatives. The methodological rigour of this study rests on the fulfilment of four quality criteria of Lincoln & Guba (1985). First, credibility (internal validity) was ensured by methods triangulation using different data collection methods and by

researcher triangulation continuously reflecting upon the interview process and analysis to ensure that the analysis reflected the data. Second, transferability (external validity) was ensured by providing contextual information, so it is possible appraise whether the findings are applicable to other contexts, situations, times and populations. Third dependability was ensured by describing in details the research design, data collection and analysis. Finally, confirmability was established by a constant reflexive account throughout the entire research process about the researcher's position and role.

During data analysis findings were presented to managers and clinicians (managers of nursing, doctors, physiotherapy, neuropsychology and occupational therapy) at the rehabilitation department, enabling their involvement in reflecting about how to make use of the different relatives' positions in these goal-setting meetings. This was relevant, because of reorganization of the interdisciplinary goal-setting meeting in the unit aiming to involve all relatives more. Previously relatives were not part of the interdisciplinary goal- setting meetings, but due to a greater organizational focus on relatives' involvement, acknowledging the importance of meeting the relatives' diverse needs to get involved in the rehabilitation, the management group had prioritized this change. The triangulation of involving the managers and clinicians as co-investigators somehow validated the clinical usefulness of the findings. As an example they thought that it would be useful to use it to educate the staff, before attending meetings with relatives. It also gave the opportunity to discuss how the finding could be used in practice by the provider's in order to actually meet the relative's diverse need and to get the relatives more involved in the rehabilitation process, if that is the need. In addition a stronger focus on the providers' capability of meeting the different positioned relatives were discussed.

This study only focused on relative's practice and position in the field of rehabilitation, with no focus on the position of providers or on the interactions in other places than before and after the meeting and in the meeting room. It appears reasonable to assume that it is the specific field that defines what appears and articulates different layers of one's habitus. Habitus is a series of dispositions that can be adapted to time and place, which is not captured in this study, as relatives were not observed in different places or at different time points of the day other than in relation to the meeting. In spite of the fact that we did not directly examine how the relatives acted outside of the medical field, we assume that there is a tendency toward a sense that relatives of patients with severe traumatic brain injury think, speak and perform in the medical field and to the position they hold in the social space, outside the medical field.

CONCLUSION

By identifying three different relative positions in neurorehabilitation, this study contributes a new framework for understanding how providers should meet and support relatives in rehabilitation differently in order to meet their (and thus the patients') diverse needs. Our findings highlight the importance of providers being able to differentiate relatives need for information, support and involvement. This new knowledge about different relative positions and their diverse needs for information, support and involvement is an important contribution to the clinicians working in the field of rehabilitation, because it offers a way of thinking that can assist clinicians to reflect about their own practice.

RELEVANCE TO CLINICAL PRACTICE

At an organizational level we recommend that findings from this study result in reviewing existing policies and guidelines and, where needed, develop new policies and clinical guidelines promoting and integrating relatives diverse need for information, support and involvement.

Bourdieu's relevance in clinical practice derives from his focus on the body, materiality and practice theory. Here the inter-relational perspective demonstrates how broader social space, fields and interactions are inter-related and further the theory invites for reflections on relations between the researcher and the object (Bourdieu 1992). In similar way knowledge from these studies are convertible to and can have educational implications informing nursing practitioners about patients and relatives and different strategies.

On a clinical level we stress the importance of providers receiving additional education, so they are able to integrate knowledge about different relative's position, be able to identify the different types of relatives, and adjust the information to the needs of each patient and relative. In this way, relatives might feel involved, listened to and that will potentially could increase their satisfaction with treatment and care and thus able to communicate more effectively preventing misunderstandings.

Furthermore, findings from this study may assist further research in patient and relative involvement.

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IMPACT STATEMENT

What does this paper contribute to the wider global clinical community?

- This paper contributes to insight about the importance of integrating knowledge of different relatives positions in the planning of rehabilitation in order to meet the relatives' (and thus patients) diverse needs
- It provides insight into how relatives' diverse strategies need to be acknowledged by the healthcare professionals in order to provide the optimal information, emotional and practical support
- Identification of relatives' positions enables clinicians to interact, communicate, and involve relatives to adult patients' with traumatic brain injury in the decision-making in the rehabilitation process

Table 1. Characteristics of the patients and relatives

Patient ID	Gender	Age	Relation	Relatives	Relatives occupied
1	Male	52	Siblings	Sister	Yes
2	Male	29	Mother-son	Mother	Yes
3	Female	39	Cohabiting	Cohabiting male	Yes
4	Male	38	Married	Wife	No
5	Male	26	Married	Wife	Yes
6	Male	72	Daughter-Father	Daughter	Yes
7	Male	18	Parents	Mother and father	Yes
8	Male	59	Cohabiting	Cohabiting Female	Yes
9a	Male	31	Mother-son	Mother	Yes
9b	Male	31	Father-son	Father	Yes

Table 2. Topics from the semi-structured interview guide

Part one (first interview with the relative)
Upbringing
Educational background
Economic background
Social networks
Past experience with illness and the healthcare system
Part two (follow-up interviews with the relative)
Current status of the disease and rehabilitation process
Relationship and interaction with the providers
Relatives experience of participation and involvement in the decision-making process

Table 3. Example from the matrix analysis, in the category 'relatives' relation to the patients illness'

The warrior	The observer	The hesitant
• The mental and cognitive body is important for *the warrior.* The mental and cognitive dysfunction associated with a TBI was a dominant concern to the relatives, which means that they are cultural inclined.*"* • Participates actively in training and during ward rounds where they are part of a professional back-and-forth with the providers	• The observer participates in training and during ward round if they happen to be present in the department and participation is therefore not an active option.	• Concerned about the physical disability, rather than the mental and cognitive disability, which means that they are more inclined towards the functional and physical body. • Does not participate or rarely participate during the training sessions or during ward rounds and therefore appears to be passive for involvement in care and treatment.

Appendix C Paper III

Title: Relatives' involvement in neurorehabilitation: facilitators and barriers

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Relatives' involvement in neurorehabilitation: facilitators and barriers

INTRODUCTION

Traumatic brain injury

Traumatic brain injury (TBI) is associated with high social and economic costs due to long-term disability and death[1]. Patients with moderate to severe TBI often have physical impairments and disabilities as well as behavioral, social, and cognitive sequelae that require long-term rehabilitation[2]. These impairments affect patients' participation in the decision-making process, and relatives become important participants, providing a voice for the patient and acting as a proxy to advocate for the patient[3].

Changing of the welfare state

In contemporary western healthcare systems, individuals are increasingly encouraged to exercise greater control over their own healthcare decisions and there is the expectation that they will be active partners in care[4]. There is also an expectation of greater family involvement to relieve pressure on the healthcare system[4,5]. These expectations, may however, have negative consequences for those with fewer resources because they may have difficulties meeting these expectations (e.g. few family resources). The assumption that everybody can take responsibility and want to be involved in their own healthcare misses the fact that that not everyone is capable of possessing and/or activating resources.

Involvement

Involvement of patients and relatives is desirable, appropriate, and required by health policies; patient involvement is considered important with respect to political ideas, ethical principles and research in healthcare[6]. Involvement is a complex and multifaceted concept and is often used interchangeably with the concept of participation. It is, however, evident that providers and service users understand and practice user involvement in different ways according to individual ideologies, circumstances, and needs[5].

There is a range of interpretations of how, and the extent to which, patients and relatives can be involved in their own and others' treatment, and in the decision-making process. Taking a patient-centered frame of reference, Boykins defines involvement as a partnership between patients, relatives, and providers, focusing on patients' (and relatives') values, preferences, and needs[7]. In other studies, different concepts like 'consumer involvement'[8], 'patient participant' [9], and 'empowerment'[10] are used to illustrate how patients' and relatives' experiential knowledge needs to enter into a potentially beneficial dynamic process with providers to ensure the best treatment and care and to meet patients' informational and emotional needs. Thus, involvement of relatives in the rehabilitation process could be understood as involvement of relatives as a resource in the patient's course of disease, which is particularly important if the patient is unconscious, as are many patients with a TBI in the early stages. Furthermore, we suggest that involvement includes actively involving patients and relatives in goal-setting: defining their wishes, making an action plan to achieve their goals, and making decisions about their own care[11-13]. Several facilitators and/or barriers to patients´ and relatives´ involvement have been identified in the literature.

Facilitators of involvement in the rehabilitation process

Patient and relative involvement enables patients and relatives to interact with healthcare providers (hereafter called providers), in particular, nurses, as they are always present, which creates possibilities of developing trusting relationships. Thus, involvement is central to nursing practice, mainly because nurses can facilitate patient involvement [14]. Effective involvement requires that nurses have sufficient knowledge of patients' and relatives' wish for involvement and that patients and relatives can genuinely influence decision-making processes[14]. Furthermore, trust and respect between nurses/providers and patients/relatives are important for participation in care decision-making[15]. An equal, mutual, safe and trusting relationship with nurses/providers creates the potential for individually tailored involvement that matches patients' and relatives' preferences and is important for promoting active participation[16].

A facilitator of involvement increases the competence of relatives, because active involvement of relatives is important for the patient's rehabilitation outcomes[17, 18] Fisher et al. (2017) suggest increasing relatives' competence to address unmet informational and practical support needs that they might have, but also to benefit individuals with a brain injury by optimizing clinical outcomes[19]. Author (2018) found that some relatives perceive their role in the rehabilitation process as that of lawyer, guardian, extended arm, coordinator, and instrument[11]. Similarly, Oyesanya and Bowers (2017) have shown that relatives of patients with TBI perceive their role as protecting the patient's physical safety (with respect to re-injury, fatigue, or overstimulation) and emotional safety (e.g. by influencing the selection of staff)[17].

Lastly, individually tailored rehabilitation may result from involvement in the rehabilitation process. Knowing the patient and his or her relatives makes individually tailoring rehabilitation easier[16].

Barriers to involvement in the rehabilitation process

Previous research shows that relatives of patients with a TBI often suffer from feelings of anxiety and depression, which may create barriers to involvement. In a study of 27 Italian relatives of 25 patients with TBI, Moretta et al. (2017) found that relatives had a high occurrence of depressive symptoms and anxiety, which emphasizes the need for appropriate psychological and cognitive supporting therapies for such relatives, also considering their complicated involvement in clinical decision-making and providing care[20]. Their findings, like those of Author (2018), show that relatives with a relatively much cultural capital can more effectively navigate the rehabilitation process and interactions with providers than relatives with less cultural capital[11]. Cultural capital refers to an individual's educational qualifications and skills, practices, and knowledge that are considered legitimate as defined by dominant groups within healthcare[21]. This might create a barrier for involving relatives with less cultural capital, who do not have those characteristics (e.g. being proactive, having knowledge of medical vocabulary, and/or efficient communication skills) to accrue benefits in the healthcare field [22]. Cultural capital or resources affect those who are socially disadvantaged to the point that they may be excluded from accessing healthcare [23]. Cultural capital has been linked to advantage and disadvantage in health, healthcare utilization, and health-promoting behaviors[24]. Additionally, Ashley (2004) found that it is important to determine whether relatives wish to be involved, whether they are able to be involved, and the degree of involvement they wish to have, because not all relatives have the wish, ability, or need to be involved[25]

.

Another potential barrier could be nurses' competence levels[15] especially if the nurses do not have the competence to support their patients' individual preferences in the best way[16]. Keatinger et al. (2002) found that patients considered communication to be the principal barrier to successful partnerships between patients and relatives and concluded that nurses' lack of communication skills was a barrier to involvement[26]. Lastly, the organizational and work

environment can influence patient and relative involvement negatively, for example, if there is lack of time[15].

Theoretical framework

The theoretical framework underlying the present study was Bourdieu's theory, especially the conceptual triad of habitus, capital, and field.

Bourdieu's concept of habitus, the system of dispositions, can be understood as 'the strategy generating principle enabling agents to cope with unforeseen and ever-changing situations'. It is explained as the 'ensemble of schemata of perception, thinking, feeling, evaluating, speaking and acting that structures all expressive, verbal, and practical manifestations and utterances of a person'[21]. An individual's strategies should be understood as the options an individual has, which according to Bourdieu can be activated on a cognitive or bodily level when individuals in the field strive to maintain or improve their position or prevent its devaluation [27].

According to Bourdieu, individual or group possession of different amounts of capital and the amount and distribution of capital determine an individual's position and positioning in the healthcare field. In the present case, this is reflected in patients either being able or not to draw on relatives' resources. Capital is evident as three fundamental types: economic capital (e.g. generated wealth, property rights), cultural capital (e.g. educational qualifications, style of speech, skills, taste) and social capital (e.g. network of connections, social obligations)[27]. Bourdieu's concept of field is defined as 'a network, or a configuration, of objective relations between positions'[28]. A field is a social arena, with its own set of positions and practices and struggles for position, where some individuals are dominant and others are dominated [28]. The position each individual has in the field results from interaction between the specific logic and rules of the field and the individual's habitus and forms of capital[21].

Using these Bourdieusian concepts as a framework enabled analysis of what is actualized in interaction between relatives and providers in neurorehabilitation and how that influenced the relatives' involvement.

Purpose

The purpose of this paper is to identify facilitators and barriers that differently positioned relatives face in their involvement in the rehabilitation process.

METHODS

This study is based on two exemplary cases.

Setting

The study was conducted in a 22-bed highly specialized rehabilitation department for patients with severe TBI at a university hospital in Denmark from November 2016 to September 2017.

Participants

Two cases of study participants were selected from 11 relatives of patients with severe TBI with impaired consciousness followed from admission to sub-acute rehabilitation. The two cases represent maximum variation (high and low) in relation to capital volume and composition of capitals, and are supported by data from other similarly positioned individuals from the study. A total of 11 participants were recruited consecutively in collaboration with the interdisciplinary management group of the rehabilitation department; the participants comprised three men and eight women. The relationship between patients and relatives varied (e.g. sister, son/daughter, mother, father, cohabitant, and spouses) but included mostly parents and spouses.

Data collection

Data consisted of participant observation and semi-structured interviews.

Participant observation

The first author (author) attended meetings that were part of in-patient rehabilitation and which were planned approximately every three weeks. The meetings included key focal points because this is where decision-making regarding rehabilitation takes place. Typical participants in the meetings were relatives along with the rehabilitation team (e.g. physicians, nurses, occupational therapists, physiotherapists, speech therapists, and neuropsychologists). A theory-based observation recording schedule was constructed focusing on interactions between relatives and providers with particular attention to how participants were involved depending on their habitus and capitals. Field notes were taken during the meetings. Twenty-two meetings were observed. The meetings were scheduled for 30 minutes and lasted between 20 and 46 minutes.

Interviews

A semi-structured interview guide was constructed that enabled exploration of patients' and relatives' experiences of interactions with providers, experiences of involvement and information, as well as decision-making during in-hospital rehabilitation. All interviews were conducted by the first author at the rehabilitation department, and the number of interviews with each relative varied from two to three depending on admission duration. Initial interviews focused on questions related to the patient's upbringing and educational background, past experience with illness and the health system, dispositions on exercise, diet, alcohol, medicine and smoking, economic background, and social networks. Follow-up interviews focused on the relatives' experiences of their own involvement, information, and decision-making during in-hospital rehabilitation. A total of 23 interviews, lasting 23-140 min., were recorded digitally and transcribed verbatim.

Data analysis

Analysis of interviews and observation field notes was undertaken using qualitative content analysis following Graneheim and Lundman (2004)[29]. Data were managed in the computer software system NVivo version 10 (QSR International). The theoretical framework underpinning the analysis was Bourdieu's conceptual triad of habitus, capital and field, which can explicate social action[30]. The triad was therefore applied to the data; it provided a relational approach to the analysis, as it described how practices in neurorehabilitation (providers-relatives) are interrelated in the field of healthcare (e.g. the physical and organizational context, relations of dominance, language, values, etc.).

Ethics

The study was conducted according to the principles of the Declaration of Helsinki; it was approved by the Danish Data Protection Agency (ID 04346), and data were handled according to its requirements, and registered with the Danish Health Research Ethics Committee (ID 17000765). As the patients were not capable of giving consent, the closest relatives to the patient were contacted by the first author to obtain informed consent. All of the relatives agreed to participate in the study. Pseudonyms are used when reporting findings.

FINDINGS

This section consists of two parts, each devoted to presenting the two exemplary participant cases. The first section presents background information about the two participants and an analysis of possible facilitators and barriers that differently positioned relatives face (see Table 1).

[Table 1 near here]

Participants' history

The first participant, Anne, is the younger sister to the patient, Arnold, a 52-year-old male. Arnold suffered a fall after alcoholic intake and subsequently sustained severe TBI. On admission to the specialized rehabilitation unit, Arnold was in the state of unresponsive wakefulness syndrome (UWS)[31], meaning that he had no cognitive awareness, only showing reflex movements without response to command[31].

The other relative participant, Martin, was a cohabitant male to the patient, Marie, aged 39 years. Marie had been involved in a traffic accident where, as the driver of the car, she was in a head-on collision with a drunk driver. On admission, Maria was in a minimally conscious state (MCS) (Ibid.), which meant that she showed the first signs of minimal, inconsistent, but reproducible behavioral evidence of self or environmental awareness[32]. Neither Arnold nor Marie was cognitively able to participate in the interdisciplinary meetings (hereafter called meetings) or the interviews. Therefore, Anne and Martin's participation provided a voice for Arnold and Marie, respectively.

Anne

Anne was 51 years old. She grew up in a rural area in a traditional family with both of her parents and six siblings. Anne completed primary school education, followed by a craftsman education. Despite her education, her employment was always in unskilled work. Taking these educational and employment factors into account, it can be argued that Anne's position reflects low to moderate economic and cultural capital. Anne's lifestyle can be seen as a product of her habitus and was expressed in and through her choices and preferences.

Anne was moderately privileged in housing as she lived in her own house in a rural district in Denmark. Her preferences for cultural goods were crime novels, watching TV,

documentaries and she preferred Danish films. Anne had moderate distinctive preferences in food, for example, traditional Danish food. Anne did not do any form of exercise. Anne did not have any preferences in terms of cars and owned a small older car. Anne used the internet sparsely, primarily to read mail and to 'google' different topics. Her leisure time was spent around the house, garden and family (e.g. daughters and grandchildren). Anne's overall position can be characterized as 'hesitant': primarily reactive to decision-making processes and uncertain of roles (Author, 2018).

Anne's opportunities for being involved

Knowledge about patient

Anne had thorough knowledge about Arnold's former history and their family history related to sickness/illness, as well as a close relationship with her brother: 'Arnold and I, we stick together'. This close relationship positioned Anne as having the expertise to be her brother's voice: 'I have always been there for Arnold (laughing) to be honest, yes I have'. Anne believed in authority, had trust and confidence in providers, and did not challenge providers' decisions, which can initially create a good partnership.

Anne's barriers to being involved

Relation to the providers

Anne seemed to have a barrier to being involved in how she interacted with the providers. Her relationship with the providers was based on one-way communication and humility to expertise, trusting that providers were well-equipped to manage Arnold's care. Anne considered the providers as experts in the field of rehabilitation, and did not ask questions or raise critical issues in the meetings about treatment and decisions. In the interview, Anne stated that she found it difficult to express her wants and needs, and that she had never been able to do that in her life.

Anne also stated that she did not know the purpose of the meeting and therefore she was not prepared for what was going to happen and what kind of questions might be relevant to ask. Anne also indicated that she had never asked many questions in her life and that she would adopt a trusting relationship to the nurses, for example, so she could feel confident asking questions. Nonetheless, Anne did not communicate cultural skills and attributes in ways that were recognizable or usable to the providers in return for involvement. Neither did she ask questions or seek information, which may have influenced the nurses' lack of attention to, or elicitation of, Anne's wants and needs. Anne was not present in the clinic every day so it was difficult for the nurses to create a relationship with her and get to know her wants and needs. The nurses did not have much knowledge of Anne, and it was evident that the providers did not seem to spend much time with her, which had a noticeable effect on the quality of interactions, making involvement difficult. Anne, accustomed to a passive role, therefore presented a practice and behavior that might be interpreted by the providers as satisfied with the level of information and involvement, because she demanded nothing of them. The balance of power between the providers and Anne was characterized by an asymmetry, with providers having the stronger position.

Non-participant in nursing care

Despite her close relationship with her brother, Anne considered her role to be that of visitor. For example, when the nurses were in a nursing care situation with Arnold, Anne left the room. She did not perceive she had an option to be involved in his care. As she described one incident herself: 'First, there came secretion out and we could see it in the corner of the mouth. And then the secretion came out of the tube. Then we called for the nurses so they came and cleaned him up'. Anne also expressed concern about being involved, for example, explaining how she asked providers for help with repositioning her brother, because his neck was in a bad position with

respect to his tracheal tube: ‘Then the nurse just said ‘you can reposition him yourself’ and said ‘we do not dare to do that’.

Possibility of presence

Anne had minimal flexibility from her workplace and was highly dependent on having an income. That meant she had to prioritize her work over visiting her brother. Not being able to visit much made her feel guilty: ‘I wish I could visit more often, but oh….’ As Anne said: ‘I feel guilty when I cannot be around as much as I would like. It was the same with my husband’.

The timing of the meetings illustrates how the system’s structures could erect another barrier to involving Anne. Anne’s work conflicted with the timing of one of the meetings at the rehabilitation unit. Although she expressed her wish to be part of the meeting where decisions were made, it was not always possible because of the organizational set-up which allowed no flexibility in terms of time. Anne tried to express her dilemma with the timing of the meeting (10 am), because she had to be at work then, but this did not change anything. When interviewing Anne about how that made her feel, she said: ‘That made me frustrated, because if the meeting could only be moved a couple of hours later, I would have been able to both take care of my work and attend the meeting’.

Difficulties expressing need for information

Another barrier to involvement related to communication and information. Anne did not express a great need for information during the meetings she was able to attend. Thus, one of the things she recommended to future patients and relatives was: ‘to be more determined to get more information, though I know it's hard [for the doctor] to say anything about [prognosis]. If only they could say something, anything’. During the meeting, standard information was given by providers, but there

was a lack of personalized information, which left Anne unsure about her brother's prognosis and future.

Because Anne was passive in her interactions and approach to Arnold's care (being reactive and unable to express her wants and needs), relative involvement was more difficult to achieve.

Martin

Martin was 47 years old, born and raised in the capital of Denmark, and was college educated. After college, Martin was in the military for two years and then completed a university degree in export engineer education, and was employed as a manager at a large electronic company. Taking these factors into account, Martin's social position could be described as middle or higher (medium to high cultural capital). It was also evident that Martin's lifestyle was a product of his habitus, which was reflected in his choices and preferences.

Martin was relatively privileged in housing. He owned his own house in the metropolitan area, suggesting that he held relatively high to medium high economic capital. Martin was relatively distinct in terms of cultural consumption, with tastes expressed as investments in trips abroad several times a year. Similarly, Martin had distinct preferences in terms of food, beverages, and other consumer goods. For example, Martin drank special beer, expensive red wine from France and Italy, and ate food from different corners of the world. Martin had distinct preferences in terms of forms of exercise and sports, such as fitness, biking, running, and sailing. He read novels, poetry collections, and Danish fiction, but rarely or never crime novels. He preferred to watch arthouse movies, such as French movies, not action movies. His interests coincided with his professional work, for example, by being engaged with art and music. Martin's preferences in cars included brands like Mercedes, Audi, or BMW. His leisure time was typically

spent on exercise, house, and family. Martin was positioned within the relative position called ‘the warrior’, characterized as being proactive and fully engaged in decisions about care, directing processes to maximize the benefit for their relative (Author, 2018).

Martin’s opportunities for being involved

Possibility of presence

Martin´s workplace provided him with maximum flexibility, enabling him to stay around Marie most of the day and night-time. Martin’s disposition manifested itself throughout the rehabilitation process as engaged and actively involved in Marie’s care, developing a range of specialist skills and knowledge during the rehabilitation process such as being legitimized to administer medication: ‘We have started a new routine. Marie is eating her dinner between 6 and 7 pm. She uses lots of energy on eating. She eats a lot of food (laughing). Afterwards, there is tooth brushing, lip balm, face cream, and lots of other stuff’. Martin supplied resources that were appreciated by the professionals: ‘It is always a pleasure collaborating with good relatives who are present all the time and do so many things. That is really special’ (provider at Marie’s meeting). Throughout the hospital stay, Martin wanted to be physically close to Marie. Thus, he found that there were more or less explicit limits/rules as to which extent he could be involved in care: ‘I was not allowed to participate in that [bath] and that…well, I am allowed to see my girlfriend naked even though she is admitted to hospital, but there is a general rule here that relatives are not allowed to be involved in bathing, so they have not allowed me access”.

Relationship with the providers

Martin activated strategies, forming an alliance with providers, especially the nurses and therapists who were around the patient and relatives all the time. These personal relationships resulted in obtaining informal insider information about future plans for Marie’s rehabilitation, outside of the

formal meetings: ‘I already heard it through the grapevine [before it was mentioned at the meeting]’. It also resulted in extra time and care: ‘I notice when they are doing something extra and when they just stick to the routines and things just need to be done, and when they really want to do something extraordinary’. The quotes indicate that Martin got personalized information and that Martin saw it as Marie receiving more services and privileges than those in standard rehabilitation. This was underscored in the meetings where Martin’s resources and involvement were enhanced by the providers, which was evident in how the meetings were dialogue-based, how the providers directed their information to Martin, asking for his opinions and thoughts, and, finally, how they encouraged Martin.

Dedication and proactivity

While Martin did not master specific biomedical language, classifications and logic, he was able to draw on cultural capital to acquire the dominant language, attitudes, and preferences. In that way, Martin showed awareness of, and adherence to, the ‘rules of the game’ and he embodied a ‘feel for the game’. He possessed cultural skills that aligned with the providers’ who, in turn, perceived him as a ‘good relative’ – an active participant in the rehabilitation process. This was often assessed on the basis of interaction (e.g. emotional relation). For example, Martin used an emotional form of appeal or investment work to achieve sympathy: ‘Marie is worth investing rehabilitation in’, emphasizing that Marie was not to blame for the accident, that she was young, healthy, in good shape, hardworking, and vegetarian. Martin’s strategy was to optimize Marie’s position in the rehabilitation field, through empathy and courtesy, so that Marie seemed worth investing in.

Martin had an active form of involvement being a proactive, dedicated participant in nursing care situations, but involvement was also relational. Martin’s strategies and attitudes might or might not

be supported and allowed by the nurses, and this also determined whether or not it was a barrier to or a promoter of involvement.

Martin's barrier to being involved

Being too proactive

Although Martin was seen as a resource by providers, this could also be a barrier to involvement. For example, Martin explained a situation where his knowledge of how much tube feeding formula Marie could tolerate without vomiting was not recognized: "I simply had to look after them [nurses] so they would realize that they would kill her if she didn´t get her food. She was vomiting and it was not working. I think it is a core nursing competency to figure out what the patient can tolerate and then deliver that knowledge to the next nurse, who delivers it to the next… There are potentially three new nurses every day. They simply just couldn´t handle it". In the quotation, Martin touched upon how lack of continuity influenced the situation: "Every time a new nurse came, I tried 'hey, you need to know' and they said 'yes, yes, we know a little more'. However, every time a new nurse took care of Marie, she vomited". Martin's knowledge and reprimanding of the nurses led to the nurses not recognizing his expertise and staying within their own routines despite Martin's knowledge of exactly how much Marie could tolerate. Martin monitored the quality of care, observing every step of the providers and trying to influence the selection of staff in order to protect Marie's physical and emotional safety. It could therefore be a barrier for involvement if Martin perceived nurses as requiring competencies and communication skills, since he was well-informed, could appear "too much", could sometimes ask difficult questions, and thus risked being judged by providers as demanding, critical, and as taking up the provider's time (e.g. asking for extra meetings with the consultant even if this was outside standardized rehabilitation).

DISCUSSION

We have identified possible facilitators and barriers that differently positioned relatives faced in being involved in the rehabilitation process. The results indicate how Anne and Martin's practices, behaviors and strategies became facilitators and barriers influencing their ability to be involved and gain advantages in rehabilitation processes. Nurses need to integrate this knowledge in the planning of their care and involvement of relatives.

Practices, behavior and strategies

Anne's practice, being reactive and unable to express wants and needs, became a barrier, whereas Martin's strategies of being proactive and explicit about his own wants and needs provided advantages in the field of rehabilitation that values holism, empathy, and caring. In the field of rehabilitation, some forms of patient and relative types – in other words, capital – are considered more important than others. According to Bourdieu, this affects individuals' strategies, attitudes, and practices[21]. In this study, this refers to relatives' as well as provider's strategies, attitudes, and practices. For example, Martin's proactive attitudes were (mostly) considered by the providers to be appropriate and were credited in the form of praise and recognition.

While Martin's strategies involved being physically present at the meetings, applying different forms of capital, using both empathy and courtesy, and speaking 1:1 (using the same language/concepts and within the same logic) with the providers, Anne's strategies were more reactive. Martin's strategies were interpreted differently by the nurses. Most of the nurses collaborated with Martin, letting him be involved in the care. Other nurses did not recognize his expertise and stayed within their professional norms and boundaries of how much and what kind of nursing activities relatives were allowed to be involved in, at times making Martin feel excluded as

a family expert and in the care of Marie. This tension between using Martin's expertise and maintaining professional expertise could result in not recognizing Martin's expertise.

In contrast to Anne (who apologized, talking about guilt, own fault, risky lifestyle), Martin could demand being involved, which was evident in his capacity to use cultural capital as a strategy in the process of involvement. Martin challenged providers and their decision making. The relationship between the providers and Martin was characterized as a power imbalance, but in contrast to Anne, Martin considered himself to be the expert on Marie's medical history. Sohlberg and Mateer (2001) suggest that professionals must be willing to "release" their role as the only expert on the team and suggest that relatives' expertise should be acknowledged and utilized in decision-making process[33]. This could potentially release time for the providers that they could invest in relatives with less capital. However, as suggested by Graff et al., providers find it easier to involve those with relatively more capital/resources, because these relatives are able to influence care and treatment[34], being capable of converting their forms of capital (e.g. cultural) into a dialogue with providers. In that way, relatives are able to optimize rehabilitation options for patients with TBI[34].

Enhancement of inequality

The results illustrate that there is a dilemma, where ideally individuals with the greatest resources should take more responsibility for their own care, with providers paying more attention to individuals with fewer resources. Paradoxically, it seems that the opposite occurs, where relatively privileged relatives gain more attention from providers, meaning that time and attention necessarily go from relatives with relatively fewer resources. Potentially, this can entrench inequality where those with fewer resources get even less and those with the most resources get even more. In that way, providers can unintentionally contribute to the reproduction of inequality.

In the case of Anne, where her close relationship to her brother is a facilitator of involvement, nurses' time investment might have made it easier for her to be involved.

Nurses may contribute to reproducing and increasing inequality, or they may contribute to decreasing inequality by investing most where the need is greatest. Relatives who are relatively privileged (e.g. with social, economic, and cultural capital) can easier navigate in the system and take action in relation to their own needs. Less privileged relatives might need additional help and support from providers. In that way, privileged relatives could provide benefit to those involved over those who are not. In order to decrease inequality, nurses need to involve relatives differently in order to compensate for relatives' unequal positions.

Social position

Existing research finds that nurses and doctors provide better treatment and care for patients the more they identify with them, depending on how close in social class to the healthcare professionals they are[35]. Furthermore, providers' perception of patients and relatives shapes alignment, or dislocation, between individual behavior and interactive styles, and broader social institutions[36]. This means that patients and/or relatives having dispositions and tastes similar to the providers' in terms of social position and capital volume are able to collaborate and communicate better with the providers and potentially obtain better treatment. This is in keeping with the findings of Dubbin et al. that patients' differential abilities deploy particular strategies to improve physician perceptions and/ or negate negative stereotypes to reduce the perceived social distance between them and improve the care received[37]. In principle, they are socially interchangeable with each other. This points to an inequality mechanism where individuals with a relatively moderate to high capital volume similar to the providers' have a stronger position and better prerequisites for understanding information about treatment options and risks than people with a relatively lower capital volume who are in a restrictive position where they may not understand what is being said to

them, which is why they do not ask questions, etc., and therefore do not receive the same relevant and adequate treatment (the hesitant position).

Core nursing competencies

Involvement is a core nursing competency, and nurses have an important role to play in supporting and balancing relatives' resources [38]. Patients' and relatives' right to influence their own healthcare is laid down in international and national laws[39]. Thus, involvement is a requirement and not immediately a choice nurses can make. Nurses may need to determine the form that relative involvement should take and take the time needed to embed within the rehabilitation process. This relationship between the relatives and nurses could with advantage been well established at the time of hospitalization. In the case of Anne, the long lasting and strong tie to her brother seems to be the only facilitator for her involvement in the rehabilitation process, which should be recognized by the nurses, even though it would require time to develop a relationship based on trust and genuine interest and ask questions about Anne and Arnold's former relationship. Nevertheless, time seems to be a key component in developing a trusting relationship. A quantitative study involving focus group interviews with nurses found that nurses experience not having enough time to communicate and develop their relationships with patients and relatives, and that this hinders the implementation of true, functioning involvement[38]. The involvement of relatives in neurorehabilitation in clinical work seems to require that nurses enter into a relationship with relatives, are genuinely curious and investigate person-specific knowledge, resulting in concrete insights into the individual's situation, including the person's values and preferences in everyday life as well as their resources[40]. If nurses applied and expanded this knowledge in daily care and in relation to relatives, it seems that relatives could be involved to meet patients' and relatives' various needs. Lastly, a supportive organization is crucial for creating a culture where involvement is an integrated and implemented part of the

nursing tasks. When involvement is considered time-consuming, organizational change may be valuable, with leaders providing support and resources to implement involvement[38].

Limitations

It could have strengthened the analysis if we had interviewed the nurses about their perspectives on facilitators and barriers in involving the differently positioned relatives in the rehabilitation process. Further research could explore this perspective qualitatively and/or quantitatively.

Another possible limitation concerns the two cases and the issue of credibility. We argue that an analysis of two cases, strategically selected, to represent relatives with maximum variation in forms of capital and referring to other relatives in the data enabled us to ensure a valid and nuanced analysis. One could argue that the two cases were not directly comparable in their positions in relation to gender, age, and biological relationship. It might make a difference whether one is male or female and if you are cohabiting or a sibling. Findings from this study may assist further research in examining how gender and biological relationships influence involvement.

IMPLICATIONS FOR FURTHER RESEARCH AND NURSING PRACTICE

We recommend that our results can be used reviewing existing policies and guidelines and, where needed, develop new policies and clinical guidelines promoting and integrating facilitators and barriers for involvement of relatives' in the rehabilitation process.

In nursing practice, we stress the importance of nurses receiving additional education, so they are able to integrate knowledge about relative's facilitators and barriers for involvement in the rehabilitation process, in order to adjust the information to the needs of each patient and relative. In this way, relatives might feel involved, listened to and that will potentially could increase their

satisfaction with treatment and care and thus able to communicate more effectively preventing misunderstandings.

Furthermore, findings from this study may assist further research in patient and relative involvement.

CONCLUSION

This study, based on two cases, has outlined different practices related to the amount and distribution of resources among relatives that function as facilitators and barriers for involvement in the rehabilitation process. Nurses need to integrate knowledge of facilitators and barriers to provide tailored involvement of relatives. Focusing nursing care on establishing a trusting relation with patients and relatives at the very beginning of hospitalization may contribute to improved practices of involvement in the rehabilitation process, where involvement is based on identification of the relative's needs, and where support could thereby be delivered in a more tailored way. Patients and relatives are unequal in terms of socioeconomic resources, and this study suggests that nurses should compensate with unequal practices to create equal opportunities for involvement of all relatives, which means addressing the barriers, regardless of the individual's resources and position.

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Table 1: Facilitators of and barriers to being involved in the rehabilitation process

	Anne	Martin
Facilitators of involvement	Knowledge about patient (former history, family history related to sickness/illness)	Proactive (action and result oriented behavior) Participating in nursing care situations Personalized information provided Explicit about own wants and needs Maximal flexibility from workplace Possesses cultural skills that align with the providers
Barriers to involvement	Reactive (passive role of involvement) Non-participant in nursing care situations Standard (not personalized) information provided Unable to express own wants and needs Time-consuming Minimal flexibility from workplace	Being too proactive Lack of respect for family expertise

Appendix D Overview of literature included in systematic review

Author/ year/ Country	Population	Design	Results
Camicia et al. (2018) **USA**	12 family members of stroke patients admitted to an inpatient rehabilitation facility.	Exploratory triangulation (interviews and survey)	Two major themes were identified: providing family-centered care, and feeling prepared to care for the patient at home after discharge.
Graff et al. (2017) Denmark	Twenty Participants with mild, moderate and severe TBI were included from a level I Trauma Center in Denmark at 1–4 years post-injury.	Qualitative	Three main themes emerged during analysis: A new life, Family involvement, and Rehabilitation impediments. These themes and their sub-themes described the patient perspective of TBI and rehabilitation post hospitalization. Participants reassessed their values and found a new life after TBI. Family caregivers negotiated rehabilitation services and helped the participant to overcome barriers to rehabilitation. Although participants were entitled to TBI rehabilitation, they had to fight for the services they were entitled to

Manskow, U et al. (2017) Norway	80 family members to patients with severe traumatic brain injury participated in the study – (GCS) <8. Patient data was collected from a national cohort study.	Quantitative	Total burden increased between years 1 and 2 post-injury (P = 0.04). Thirty percent of the family members reported an increased burden, 55% were stable, and 15% had a decrease in burden between the two follow-up times. Logistic regression analyses revealed that experiencing loneliness was an independent predictor of increased burden from 1 to 2 years post-injury (OR = 4.35, P < 0.05). Life Satisfaction was lower at the 2-year follow-up than at 1 year (p = 0.03)
Oyesanya, T. (2017) USA	The systematic review is comprised of 11 qualitative studies which were found through searching seven databases. The studies revolve around patients with moderate to severe TBI. No studies were excluded on the basis of quality appraisal.	Systematic review	Findings on the patient experience showed patients had negative perceptions of the rehabilitation environment and a perceived need for information. Findings on the family experience included difficulty adjusting after the patient's injury, a desire to be involved in the patient's care, mixed feelings about staff support and a high perceived need for information.
Lutz et al. (2017) USA	81 interviews with 40 stroke family caregivers caring for 33 stroke patients.	Qualitative	A framework in three-steps for improving caregivers' readiness was develop. The three steps included; 1) conducting a Risk assessment 2)

			Assessing Patient Needs 3) Assessing Caregiver Commitment and capacity.
Doser, K & Norup, A (2016) Denmark	44 Danish caregivers of patients with severe TBI participated in the study – (GCS) <9. The caregivers were contacted 3-6 years post-injury.	Quantitative	Medium, high and low levels of burden were observed in 45%, 16% and 39% of family members, respectively. Higher burden was seen in caregivers of patients with more severe injuries, who spent more time on caregiving and reported more unmet needs. Overall, spouses spent significantly more time taking care of their family member than parents and reported higher levels of burden.
Kuipers, P (2014) Australia	This study comprised individual and group interviews. The interviews included family members of 14 ex-patients with moderate to severe TBI (GCS) <12.	Qualitative	Findings clearly confirmed the significance of engaging family members in inpatient rehabilitation, and specifically reinforced the importance of informational, emotional, practical and peer support. However, the key finding of the study was the importance of hope, and the need for rehabilitation professionals to foster hope.
Young et al. (2014) USA	Interviews with 14 spouses pre- and post discharge stroke rehabilitation.	Qualitative	Twelve domains of assessment were identified; strength of dyad relationship, understanding of and willingness to perform care, existing physical and mental health

			issues, pre-stroke roles and responsibilities, accessibility of the home environment, availability of informal support, financial resources, pre-strike caregiver experiences, sustained capacity to provide care, strategies for self-care, stroke as a crisis and long-term meaning of stroke.
Dillahunt-Aspillaga et al (2013) USA	53 adult caregivers (26-81 years) of a family member who has sustained a TBI.	Quantitative	Significant differences were found between the stage of caregiving, stage of recovery and pressing concerns reported by the caregiver, which indicate that caregiving and related family needs are ever-present and continue to change over time. Findings also highlight that a large number of caregivers may not report needs or concerns when providing care for persons with TBI.
Cameron et al. (2012) Canada	Interviews with 24 family caregivers and 14 healthcare professionals.	Qualitative	Three main themes emerged during analysis: Types and intensity of support needed, who provides support and the methods providing support and primary focus of care.
LeFebvre & Levert (2012) Canada	150 participants (individuals who sustained TBIs, their loved ones, and their healthcare professionals)	Qualitative	Individuals with TBIs and their loved ones have a need

			for information that is present throughout the continuum of care, as well as a need for support, and a collaborative relationship with health care professionals experienced by individuals with TBIs and their loved ones.
LeFebvre & Levert (2012) Canada	48 participants: 19 relatives, 29 healthcare professionals.	Qualitative	Relatives need information on health problems (diagnosis, prognosis and factors influence this) Relatives need specific, quality services and continuity of services
O'Callaghan et al. (2011) Australia	184 careers	Quantitative	The results of this study showed that as careers transitioned through the healthcare journey with their family member with TBI, health services progressively declined. As this occurred, careers' satisfaction with services reduced, while their responsibilities for caring increased.
Keenan, A & Joseph, L. (2010) Canada	25 family members who were associated with 15 patients with (GCS) < 9. Data are reported from 44 interviews conducted at two-time periods: discharge from intensive care unit (Time 1) and discharge from acute care	Qualitative	Family members identified a variety of needs during acute hospitalization period. Thematic analysis at (Time 1) identified four main themes that described the trajectory of the families' experiences: getting the news, uncertainty, making sense

	facility to home or rehabilitation (Time 2).		of the news and moving on. At (Time 2), themes of the family experience included: uncertainty, looking for progress, transition and letting go/building a new connection. Themes that identified the needs of families included managing life, involvement in care and holding on to hope. Support required by the family included the need for information, professional support and community support. Families had intensive needs in the acute phase of the injury and their needs changed over time.
Kim, JW & Moon, SS (2008) USA	123 South Korea family caregivers caring for stroke patients completed Family Needs Questionnaire	Quantitative	Family caregivers caring for their patients in te acute phases, the family caregivers caring for their patients in the acute rehabilitation phase perceived the need for healt information as more important than those in the postacute phases. Family caregivers caring for patients in the acute rehabilitation phase were less satisfied with community network support and family support than those in postacute phase. Family caregivers

			caring for their patients in outpatient clinics services showed the lowest satisfaction of their needs (health information, emotional support, instrumental support and professional support) compared with those in inpatients facilities or day hospitals.
Jumisko, E. Lexell, J. & Söderberg, S. (2006) Sweden	Twelve people with moderate or severe TBI and eight of their close relatives were interviewed.	Qualitative	The results were described by the means of two themes: being excluded and missing confirmation. People with TBI and their close relatives had experiences of being avoided, being ruled by the authorities, being met with distrustfulness and being misjudged. They also searched for answers and longed for the right kind of help. People who listened to them, believed them and tried to understand and help them were appreciated.

Appendix E Information to participants stroke

Hvidovre Hospital

KLINIK FOR HØJT SPECIALISERET
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Dec.2015

Information til patient omkring projektet "Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller hjerneblødning"

Kære Patient

Jeg vil hermed invitere dig til at medvirke i et sundhedsvidenskabeligt forskningsprojekt "*Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller hjerneblødning*". Jeg vil samtidig bede om tilladelse til at anvende oplysninger fra patientjournalen vedrørende din baggrund (sygdomshistorie, uddannelse, alder, køn, beskæftigelse og lign.).

Projektets formål er at belyse rehabiliteringsforløb for patienter med en blodprop i hjernen eller hjerneblødning. Jeg vil specielt interessere mig for de beslutninger, der tages ved hvert møde under indlæggelsesforløbet, samt på samspillet mellem patient, pårørende og personalet i afdelingen (fysioterapeut, ergoterapeut, læge, sygeplejerske og andre fra dit team).

Projektet er en del af mit Ph.d.-projekt, som skriver sig ind i Forskningsnetværket PHLEGETHONs samlede projekt, ledet af professor, Kristian Larsen. Netværket involverer forskningsinstitutioner i både Danmark og Norge, der på forskellig vis og fra forskellige perspektiver bidrager til at undersøge forskningsfeltet.

Hvad indebærer det at deltage i projektet?

Jeg deltager som observatør ved dit første stuegangsmøde (DIS) i rehabiliteringsafdelingen og ved de efterfølgende tværfaglige stuegangsmøder, samt ved udskrivningskonferencen. Mit fokus under møderne vil primært være på de faglige beslutningsprocesser og på samspillet mellem dig, dine pårørende og personalet i afdelingen. Jeg vil altså ikke deltage aktivt i møderne.
Umiddelbart efter møderne, eller senest dagen efter, vil jeg interviewe dig. Tid og sted for interviewene aftales nærmere efter dit ønske. Under interviewene vil jeg stille spørgsmål til din oplevelse af det netop afholdte møde, samt forskellige andre forhold vedrørende indlæggelsesforløbet. Interviewet vil blive optaget som lyd-fil, så jeg efterfølgende kan huske hvad vi har talt om. Denne optagelse vil blive behandlet fortroligt, og du vil ikke kunne blive genkendt i det færdige resultat af undersøgelsen.

Er der risici, bivirkninger og ulemper?

Nej, der er ingen risici, bivirkninger eller ulemper forbundet med din deltagelse i projektet

Hvad er nytten af forsøget?

Projektet er vigtigt, fordi det kan bidrage med et patient- og pårørende perspektiv på indlæggelsesforløbet på en rehabiliteringsafdeling, hvilket ikke tidligere er undersøgt hos patienter med en blodprop i hjernen og hjerneblødning.

Ved deltagelse vil du primært være med til at forbedre sundhedstilbuddene for fremtidige patienter, men du vil også få mulighed for at tænke over dit eget forløb.

Patientens sikkerhed og rettigheder:

Alle data i projektet behandles med diskretion og behandles omhyggeligt efter lovgivningens forskrifter. Jeg har, som forsker i projektet tavshedspligt. Når data analyseres og senere publiceres vil det ikke være muligt at genkende data fra den enkelte patient.

Du har til enhver tid ret til at trække dit samtykke tilbage, hvis du fortryder, at du har sagt ja til at deltage. Denne beslutning vil ikke have indflydelse på din fremtidige behandling i afdelingen eller personalets behandling af dig.

Hvem har ansvaret for undersøgelsen og kan kontaktes ved spørgsmål?

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Hvidovre Hospital
Udefunktion fra Rigshospitalet

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Dec.2015

Information til pårørende omkring projektet "Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller hjerneblødning"

Kære pårørende

Jeg vil hermed invitere dig, som nærmeste pårørende til at medvirke i et sundhedsvidenskabeligt forskningsprojekt "*Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller hjerneblødning*". Jeg vil samtidig bede om tilladelse til at anvende oplysninger fra patientjournalen vedrørende din pårørendes baggrund (sygdomshistorie, uddannelse, alder, køn, beskæftigelse og lign.).

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Jeg deltager som observatør, ved det første stuegangsmøde (DIS) i rehabiliteringsafdelingen og ved de efterfølgende tværfaglige stuegangsmøder, samt ved udskrivningskonferencen. Mit fokus under møderne vil primært være på de faglige beslutningsprocesser og på samspillet med dig som pårørende, din pårørende, som er patient og personalet i afdelingen. Jeg vil altså ikke deltage aktivt i møderne.
Umiddelbart efter møderne, eller senest dagen efter, vil jeg interviewe dig. Interviewet vil blive optaget som lyd-fil, så jeg efterfølgende kan huske hvad vi har talt om. Tid og sted for interviewene aftales nærmere efter jeres ønske. Under interviewene vil jeg stille spørgsmål til din oplevelse af det netop afholdte møde, samt forskellige andre forhold vedrørende indlæggelsesforløbet. Denne optagelse vil blive behandlet fortroligt, og du vil ikke kunne blive genkendt i det færdige resultat af undersøgelsen.

Er der risici, bivirkninger og ulemper?

Nej, der er ingen risici, bivirkninger eller ulemper forbundet med din deltagelse i projektet

Hvad er nytten af forsøget?

Projektet er vigtigt, fordi det kan bidrage med et patient- og pårørende perspektiv på overgangene i et indlæggelsesforløb på rehabiliteringsafdelinger, hvilket ikke tidligere er undersøgt hos patienter med en blodprop i hjernen eller hjerneblødning.

Ved deltagelse vil du primært være med til at forbedre sundhedstilbuddene for fremtidige patienter, men du vil også få mulighed for at tænke over dit eget forløb.

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Patientens sikkerhed og dine rettigheder som pårørende:

Alle data vedrørende patienterne i projektet behandles med diskretion og behandles omhyggeligt efter lovgivningens forskrifter. Jeg har, som forskeren i projektet, tavshedspligt. Når data analyseres og senere publiceres vil det ikke være muligt at genkende data fra den enkelte patient.

Du har til enhver tid ret til at trække dit samtykke tilbage, hvis du fortryder, at du har sagt ja til at deltage. Denne beslutning vil ikke have indflydelse på patientens fremtidige behandling i afdelingen eller personalets behandling af dig som pårørende.

Hvem har ansvaret for undersøgelsen og kan kontaktes ved spørgsmål?

Rikke Guldager
Forskningsansvarlig sygeplejerske, Cand.cur, Ph.d.-studerende
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Appendix F Information to participants TBI

Hvidovre Hospital
Udefunktion fra Rigshospitalet

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Nov.2016

Information til pårørende omkring projektet "Patient og pårørende perspektiv på rehabiliteringsforløb efter en hjerneskade"

Kære pårørende

Jeg vil hermed invitere dig, som nærmeste pårørende til at medvirke i et sundhedsvidenskabeligt forskningsprojekt "*Patient og pårørende perspektiv på rehabiliteringsforløb efter en hjerneskade*". Jeg vil samtidig bede om tilladelse til at anvende oplysninger fra patientjournalen vedrørende din pårørendes baggrund (sygdomshistorie, uddannelse, alder, køn, beskæftigelse og lign.).

Projektets formål er at belyse rehabiliteringsforløb for patienter med en hjerneskade. Jeg vil specielt interessere mig for de beslutninger, der tages ved hvert møde under indlæggelsesforløbet, samt på samspillet mellem patient, pårørende og personalet i afdelingen (fysioterapeut, ergoterapeut, læge, sygeplejerske og andre fra din pårørendes team).

Projektet er en del af mit Ph.d.-projekt, som skriver sig ind i Forskningsnetværket PHLEGETHONs samlede projekt, ledet af professor, Kristian Larsen. Netværket involverer forskningsinstitutioner i både Danmark og Norge, der på forskellig vis og fra forskellige perspektiver bidrager til at undersøge forskningsfeltet.

Hvad indebærer det at deltage i projektet?

Jeg deltager som observatør, ved det første møde i rehabiliteringsafdelingen, ved de efterfølgende tværfaglige møder, samt ved udskrivningsmødet. Mit fokus under møderne vil primært være på de faglige beslutningsprocesser og på samspillet med dig som pårørende, din pårørende, som patient og personalet i afdelingen. Jeg vil altså ikke deltage aktivt i møderne.
Umiddelbart efter møderne, eller senest dagen efter, vil jeg interviewe dig. Interviewet vil blive optaget som lyd-fil, så jeg efterfølgende kan huske hvad vi har talt om. Tid og sted for interviewene aftales nærmere efter dit ønske. Under interviewene vil jeg stille spørgsmål til din oplevelse af det netop afholdte møde, samt forskellige andre forhold vedrørende indlæggelsesforløbet.
Denne optagelse vil blive behandlet fortroligt, og du vil ikke kunne blive genkendt i det færdige resultat af undersøgelsen.

Er der risici, bivirkninger og ulemper?

Nej, der er ingen risici, bivirkninger eller ulemper forbundet med din deltagelse i projektet

Hvad er nytten af forsøget?

Projektet er vigtigt, fordi det kan bidrage med et patient- og pårørende perspektiv på overgangene i et indlæggelsesforløb på rehabiliteringsafdelinger, hvilket ikke tidligere er undersøgt hos patienter med en hjerneskade.
Ved deltagelse vil du primært være med til at forbedre sundhedstilbuddene for fremtidige patienter, men du vil også få mulighed for at tænke over dit eget forløb.

Hvidovre Hospital

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Patientens sikkerhed og dine rettigheder som pårørende:

Alle data vedrørende patienterne i projektet behandles med diskretion og behandles omhyggeligt efter lovgivningens forskrifter. Jeg har, som forskeren i projektet, tavshedspligt. Når data analyseres og senere publiceres vil det ikke være muligt at genkende data fra den enkelte patient.

Du har til enhver tid ret til at trække dit samtykke tilbage, hvis du fortryder, at du har sagt ja til at deltage. Denne beslutning vil ikke have indflydelse på patientens fremtidige behandling i afdelingen eller personalets behandling af dig som pårørende.

Hvem har ansvaret for undersøgelsen og kan kontaktes ved spørgsmål?

Rikke Guldager
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Appendix G Informed consent sheet for participants

Hvidovre Hospital
Udefunktion fra Rigshospitalet

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Informeret samtykke erklæring

Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller en hjerneblødning

Erklæring fra den person, som afgiver stedfortrædende samtykke:
Jeg har fået skriftlig og mundtlig information og jeg ved nok om projektets formål, metode, fordele og ulemper til at give mit samtykke.

Jeg ved at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage uden at patienten mister nuværende eller fremtidige rettigheder til behandling.

Jeg giver hermed mit samtykke til, at ..... (Patientens navn), deltager i forskningsprojektet " Patient og pårørende perspektiv på rehabiliteringsforløb efter en blodprop i hjernen eller en hjerneblødning" og jeg har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Oplysning om min tilknytning til patienten:.....

Navnet på den person, der giver stedfortrædende samtykke: .....

Dato:..... Underskrift:.....

Erklæring fra den, der har afgivet informationen:
Jeg erklærer, at der er givet mundtlig og skriftlig information om projektet.

Navnet på den, projektansvarlige: .....
Dato:..... Underskrift:.....

Projektansvarlig sygeplejerske, Cand.cur., Ph.d.-studerende
Rikke Guldager
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Hvidovre Hospital
Udefunktion fra Rigshospitalet

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Informeret samtykke erklæring

Patient og pårørende perspektiv på rehabiliteringsforløb efter en hjerneskade

Erklæring fra den person, som afgiver stedfortrædende samtykke:
Jeg har fået skriftlig og mundtlig information og jeg ved nok om projektets formål, metode, fordele og ulemper til at give mit samtykke.

Jeg ved at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage uden at patienten mister nuværende eller fremtidige rettigheder til behandling.

Jeg giver hermed mit samtykke til, at ..... (Patientens navn), deltager i forskningsprojektet " Patient og pårørende perspektiv på rehabiliteringsforløb efter en hjerneskade" og jeg har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Oplysning om min tilknytning til patienten:.....

Navnet på den person, der giver stedfortrædende samtykke: .....

Dato:..... Underskrift:.....

Erklæring fra den, der har afgivet informationen:
Jeg erklærer, at der er givet mundtlig og skriftlig information om projektet.

Navnet på den, projektansvarlige: .....
Dato:..... Underskrift:.....

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Hvidovre Hospital
Udefunktion fra Rigshospitalet

KLINIK FOR HØJT SPECIALISERET
NEUROREHABILITERING &
TRAUMATISK HJERNESKADE

Informeret samtykke erklæring
"Vindere og tabere i rehabilitering"

Jeg giver hermed min tilladelse til at medvirke i pilotprojektet " Vindere og tabere i rehabilitering" efter at være blevet mundligt og skriftligt informeret om projektet. Den indsamlede empiri bliver behandlet fortroligt og vil ikke indgå i den færdige Ph.D., men vil muligvis blive brugt i anden videnskabelig sammenhæng og da i anonymiseret form. Jeg kan til enhver tid trække min tilladelse tilbage uden at det får konsekvenser for min behandling og pleje i Sundhedsvæsenet hverken nu eller senere.

Underskrift og dato

Erklæring fra den, der har afgivet informationen:
Jeg erklærer, at der er givet mundtlig og skriftlig information om projektet.
Navnet på den, projektansvarliges navn

Underskrift og dato

Yderligere information kan fås hos;
Projektansvarlig sygeplejerske, Cand.cur., Ph.d.-studerende
Rikke Guldager
Rikke.guldager@regionh.dk
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Appendix H Observational guide

Tema	Analysepunkter	Feltnoter/kommentarer
Deltagere (Hvem)	- Relation til patient? - Køn? - Hvor mange pårørende - Hvor mange sundhedsprofessionelle - Placering - Hvordan kommer deltagerne til rummet? (for sent, til tiden, hvad kan afbryde (hvis noget) - Forstyrrelser (understøtter rummet mødeaktiviteten/ eller ej? - traktement	Aktivitets/tidsregistrering
Fysiske rammer (Hvor)	- Hvor foregår mødet? - Hvordan er rummet, herunder æstetik (hvem ejer rummet)? - Varighed af mødet? - På hvilke tidspunkt af dagen afholdes mødet? - Bliver det tydeligt markeret at der foregår et møde ex skilt på døren	
Interaktion mellem patient/pårørende/professionelle (Hvad) Mødestart/ introduktion - Hvem indleder, er ordstyrende, besluttende? - Hvad udspiller der sig under mødeopstarten? Hvad er patient/pårørende optaget af at tale om?	- Hvordan bydes patient/pårørende velkommen? ○ Hilses der? - Hvor søger de pårørende indflydelse under mødet? - Hvordan er patient/pårørendes kropssprog (Åbent/lukket, offensiv/defensiv, gestik, mimik) - Benytter patient/pårørende strategier i interaktionen med de professionelle?	Begivenhedsobservationer

Hvad opfatter de professionelle at tale om? Hvilke kapitalformer præsenterer patient/pårørende (egenskaber, besiddelser, kompetencer)? Og hvordan modtages disse? Mødeafslutning - Hvordan rundes mødet af - Hvad udspiller der sig under mødets afslutning?	(spontane tilpasninger) Fx strategier ifh. konflikter (indvendinger/afbrud)? - Hvordan og hvem løser konflikter? - Hvordan forhandles der mellem patient/pårørende og de sundhedsprofessionelle? - Hvilke udfordringer synes patient og pårørende at møde? - Hvordan kommer empatisk støtte til udtryk?	

Kommunikation/dialog - Hvilke begreber, klassifikationer og logikker er virksomme? (biomedicinsk, lægmand-hverdagsbegreber, administrativ) - Hvordan tales der om patienten og sygdommen - Tværfaglighed; hvem spiller ind med hvad. - Hvordan skifter indholdet i samtalen? - Ændrer argumenterne sig?	- Stilles der kritiske spørgsmål fra patient/pårørende eller accepteres beslutninger umiddelbart? - Hvor opnås konsensus og hvor opstår diskussion-stridspunkter? - Hvordan er dialogmetoden? - Tales der i nutid eller fremtid - Dominerer/domineren de? - Doxa?	
Observatørens rolle	- Vækker jeg opsigt? - Har jeg påvirket observationerne? - Får jeg henvendelser fra patient/pårørende? - Hvilke remedier tager jeg med? - Hvordan placerer jeg mig i feltet? - Hvad er min rolle (nærhed/distance)	

Appendix I Interview guide initial interview

Interviewguide

Briefing:

Tak fordi du har lyst til at deltage i mit projekt. Det er jeg rigtig glad for. Jeg ved det har været en lang dag allerede og at du måske er ved at være træt. Du må markere hvis det bliver for meget og så kan xx måske svare på nogle af spørgsmålene.

Jeg vil først ridse formålet op

Formålet er at belyse patient og pårørende perspektivet på rehabiliteringsforløbet hos patienter med en blodprop i hjernen eller en hjerneblødning, med fokus på de beslutninger, der tages ved hvert møde under indlæggelsesforløbet, samt samspillet mellem patient, pårørende og de sundhedsprofessionelle.

Anonymitet:

Frivilligt

Transskription

Interviewet er opdelt i to dele. Jeg starter med at spørge om en masse forskellige oplysninger, indenfor forskellige kategorier. Og dernæst taler vi mere om dit sygdoms og rehabiliteringsforløb.

Først vil jeg stille dig nogle spørgsmål om din opdragelses og uddannelsesmæssig baggrund

- Nationalitet?
- Hvad er din uddannelse, erhverv, beskæftigelse?
- Kan du lide at lytte til musik? Hvilken?
- Film? Teater? Museum? Bøger? Mad?
- Hvor ofte rejser i på ferie og hvorhen?

De næste spørgsmål handler om din tidligere erfaringer med sundhedssystemet/ erfaring med sygdom?

- Habituel helbredstilstand, herunder;
    - Motionsvaner?
    - Madvaner?
    - Alkoholvaner?
    - Medicin?
    - Rygning?
- Bruger du internettet til at søge information, så du nemmere kan forstå/stille spørgsmål til de professionelle?
- Har du rettet henvendelse til patientforeningen ”hjernesagen” eller andre patientforeninger, for information og støtte under indlæggelsesforløbet?
- Hvor aktiv oplever du, at du kan/skal være i eget indlæggelsesforløb, sygdomsbehandling, og plejeforløb.
- Har du sundhedsfaglige forbindelser? Og har du kunne trække på disse under dit rehabiliteringsforløb?

Her skal meget gerne trækkes eksempler ind fra observation af møderne. Fx jeg lagde mærke til, at du under mødet ….

De næste spørgsmål omhandler dine økonomiske forhold og sociale netværk

- Hvilken kommune er du bosat i?
- Boligform, ejer, leje, fritidsbolig?
- Hvor mange er i, i din husstand, alder på disse?
- Hvordan er dit forsørgelsesgrundlag under din sygdom?
- Hvad er dine forældres uddannelse, erhverv og beskæftigelse?
- Har du tegnet forsikringer, der kan komme dig til gode under dit sygdomsforløb fx kritisk sygdom?
- Har du nogen mennesker, der rådgiver dig, fx forsikringsmæssigt? (Ex advokat)
-

- Køn, alder, civilstatus
- Hvem er den mest centrale person i dit liv?
- Hvem er din tætteste ven/veninde?
- Hvem besøger dig under din indlæggelse?
- Hvordan gør du brug af dit netværk/hvordan oplever du, at du får støtte fra dit netværk?
-

Nu går vi over til at tale om dit sygdoms og rehabiliteringsforløb

Kan du fortælle om situationen, hvor du fik at vide, at du skulle overflyttes til denne genoptrænings afdeling, du er kommet til i dag? (fokus på indledning af mødet)

- Hvem sagde til dig du skulle overflyttes og hvad sagde vedkommende?
- Hvordan har du så oplevede at komme til dette nye sted?
- Hvordan har du oplevet indlæggelsesmødet? Velkomsten? Hvordan oplevede du mødet, som du netop har deltaget i?
- Hvordan oplevede du kommunikationen var imellem jer?
- Hvordan følte du dig modtaget?

DIS mødet

- Viste du hvad mødet i dag gik ud på inden?
- Er det altid dig der deltager til møderne?
- Fik du svar på dine spørgsmål?
- Hvad oplevede du, fyldte mest på mødet i dag?
- Hvad er du mest optaget af efter mødet i dag?
- Siddet du tilbage med nogle spørgsmål? Hvilke? (fokus på afslutning af mødet)

Ved de efterfølgende møder;

- Kan du fortælle mig om dit indlæggelses forløb indtil nu/ Er der sket noget i indlæggelsesforløbet siden vi sidst snakkede sammen?
    - Har du fået at vide hvornår du skal udskrives herfra?
    - Hvem fortæller dig om din videre plan for genoptræningen?
    - Gør du dig selv nogle tanker omkring det?

Oplevelse af mødet/interaktionen med de fagprofessionelle: Disse spørgsmål spørges til hver gang.

- Hvad oplever du går godt i samarbejdet/kommunikationen med de professionelle?
- Hvad oplever du som udfordrende i samarbejdet/kommunikationen med de professionelle?
- Hvordan oplever du at bliver inddraget i beslutninger vedr. dit rehabiliteringsforløb? Fx mål, tidspunkt, varighed?
- **Hvordan opleves det for de pårørende at sætte mål for patienten, når der eksempelvis er mange uafklarede spørgsmål?**
- Hvordan oplever du at informationsniveauet er, både i forhold til hvad der skal ske med dig under dit indlæggelsesforløb og bagefter?
- Hvis beslutninger ligger du mest vægt på?
- Hvem oplever du har (mest) autoritet?
- Hvilke ressourcer vil du pege på er vigtige i relation til dit indlæggelsesforløb?
- Oplever du at dine/dine pårørendes ressourcer inddrages i beslutningerne i dit rehabiliteringsforløb? Hvordan? Eller hvorfor tror du ikke de bliver inddraget?
- Hvordan kunne du tænke dig at bliver inddraget?

- Hvad påvirker dine muligheder for at blive inddraget som du ønsker?
- Oplever du at de behov du har, bliver indfriet? Fx oplever du at du får den genoptræning du har behov for? Arbejder i med det du synes er det vigtigste at arbejde med?
- Er møderne tilrettelagt så du har mulighed for at deltage? (til pårørende).

Fremtid/eksistentielle spørgsmål: (Stilles hver gang)

- Hvilke tanker gør du dig om fremtiden? Positive tanker samt hvad kan udfordre dig?
- Hvilke drømme har du for fremtiden i forhold til bolig, job, familie?
- Hvad synes du er allersværest/mest udfordrende i forhold til din situation/forandrede situation- hvor føler du de allerstørste udfordringer er for dig?
- I hvilke situationer oplever du, at have brug for hjælp?
- Har ulykken ændret dit syn på dig selv og dit liv?
- Hvad er anderledes fra før ulykken til i dag?
- Har du tænkt på, hvordan dit forløb adskiller sig fra andres, hvis du sammenligner med de andre der er indlagt her til rehabilitering?

Debriefing:

Tak for din/jeres deltagelse. Er der noget der er vigtigt at sige til slut? Du er velkommen til at kontakte mig ved spørgsmål.

Appendix J Interview guide follow-up interview

Interviewguide

Briefing:

Tak fordi du har lyst til at deltage i mit projekt. Det er jeg rigtig glad for. Jeg ved det har været en lang dag allerede og at du måske er ved at være træt. Du må markere hvis det bliver for meget og så kan xx måske svare på nogle af spørgsmålene.

Formål at belyse patient og pårørende perspektivet på rehabiliteringsforløbet hos patienter med en blodprop i hjernen/hjerneblødning/TBI, med fokus på de beslutninger, der tages ved hvert møde under indlæggelsesforløbet, samt samspillet mellem patient, pårørende og de sundhedsprofessionelle.

Anonymitet:

Frivilligt

Transskription

Først og fremmest kan du fortælle mig om dit indlæggelses forløb indtil nu/ Er der sket noget i indlæggelsesforløbet siden vi sidst snakkede sammen?

- Har du fået at vide hvornår du skal udskrives herfra?
- Hvem fortæller dig om din videre plan for genoptræningen?
- Gør du dig selv nogle tanker omkring det?

Oplevelse af mødet/interaktionen med de fagprofessionelle: Disse spørgsmål spørges til hver gang.

- Hvad ville du fortælle til xxx efter mødet i dag?
- Føler du dig mere afklaret om dit sygdomsforløb efter mødet i dag?
- Følte du dig bedre forberedt, nu hvor du viste hvordan mødet skulle foregå?
- Hvad oplever du går godt i samarbejdet/kommunikationen med de professionelle?
- Hvad oplever du som udfordrende i samarbejdet/kommunikationen med de professionelle?
- Hvordan oplever du at bliver inddraget i beslutninger vedr. dit rehabiliteringsforløb? Fx mål, tidspunkt, varighed?
- Hvordan oplever du at informationsniveauet er, både i forhold til hvad der skal ske med dig under dit indlæggelsesforløb og bagefter?
- Hvis beslutninger ligger du mest vægt på?
- Hvem oplever du har (mest) autoritet?
- Hvilke ressourcer vil du pege på er vigtige i relation til dit indlæggelsesforløb?
- Oplever du at dine/dine pårørendes ressourcer inddrages i beslutningerne i dit rehabiliteringsforløb? Hvordan? Eller hvorfor tror du ikke de bliver inddraget?
- Hvordan kunne du tænke dig at bliver inddraget?
- Hvad påvirker dine muligheder for at blive inddraget som du ønsker?
- Oplever du at de behov du har, bliver indfriet? Fx oplever du at du får den genoptræning du har behov for? Arbejder i med det du synes er det vigtigste at arbejde med?
- Er møderne tilrettelagt så du har mulighed for at deltage? (til pårørende).

Den måde du takler sygdomsforløbet på, er det noget du har mødt før i dit liv? Kan du komme med eksempler på det?

Fremtid/eksistentielle spørgsmål: (Stilles hver gang)

- Hvilke tanker gør du dig om fremtiden? Positive tanker samt hvad kan udfordre dig?
- Hvilke drømme har du for fremtiden i forhold til bolig, job, familie?
- Hvad synes du er allersværest/mest udfordrende i forhold til din situation/forandrede situation- hvor føler du de allerstørste udfordringer er for dig?
- I hvilke situationer oplever du, at have brug for hjælp?
- Har ulykken ændret dit syn på dig selv og dit liv?
- Hvad er anderledes fra før ulykken til i dag?
- Har du tænkt på, hvordan dit forløb adskiller sig fra andres, hvis du sammenligner med de andre der er indlagt her til rehabilitering?

Debriefing:

Tak for din/jeres deltagelse. Noget der er vigtigt at sige til slut? Du er velkommen til at kontakte mig ved spørgsmål.

Appendix K Declaration of co-authorship

CO-AUTHOR STATEMENT
DOCTORAL SCHOOL OF THE HUMANITIES

AALBORG UNIVERSITY
DENMARK

Faculty Office for Humanities and Social Sciences
Case No.: 2018-569-00023
Document no.: 110643 version 25/01/2018

Title of article	Rehabilitation capital: a new form of capital to understand rehabilitation in a Nordic welfare state
Journal	Health Sociology Review
Publication status *(submitted/accepted/ published)*	Published

Description of PhD student's contribution
Name of PhD student: Rikke Guldager

Rikke Guldager, has done most of the work with formulating/identification of the scientific problem and designing the study, including selection of methods and method development.
Rikke Guldager, has essentially done the data collection and transcribed the empirical material.
Rikke Guldager, has done most of the analysis and interpretation of the results.
Rikke Guldager wrote the first draft of the manuscript and revised the manuscript and has essentially done the finalization of the manuscript and submission.

Description of co-author's contribution
Name of co-author: Ingrid Poulsen

Ingrid Poulsen, has contributed significantly in designing the study, including selection of methods and method development, and in the analysis and in interpretation of the findings
Ingrid Poulsen has contributed significantly in revising the manuscript and in approval of the final manuscript

Description of co-author's contribution (if applicable)
Name of co-author: Ingrid Egerod

Ingrid Egerod, has critically reviewed the manuscript and gave comments for improvements during the writing process and in revision of the paper

Description of co-author's contribution (if applicable)
Name of co-author: Lone Lundback Mathisen

Lone Lundback Mathisen made the research a reality throught access to patients and has critically reviewed the manuscript during the writing process

Description of co-author's contribution (if applicable)
Name of co-author: Kristian Larsen

Kristian Larsen, has contributed significantly in designing the study, including selection of methods and method development, and in the analysis and in interpretation of the findings
Kristian Larsen, has contributed significantly in revising the manuscript and in approval of the final manuscript

Description of co-author's contribution (if applicable)
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CO-AUTHOR STATEMENT

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AALBORG UNIVERSITY
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Faculty Office for Humanities and Social Sciences
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Title of article	Relatives' strategies in sub-acute brain injury rehabilitation: the warrior, the observer and the hesitant
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Description of PhD student's contribution
Name of PhD student: Rikke Guldager

Rikke Guldager, has done most of the work with formulating/identification of the scientific problem and designing the study, including selection of methods and method development.
Rikke Guldager, has essentially done the data collection and transcribed the empirical material.
Rikke Guldager, has done most of the analysis and interpretation of the results.
Rikke Guldager wrote the first draft of the manuscript and revised the manuscript and has essentially done the finalization of the manuscript and submission.

Description of co-author's contribution
Name of co-author: Karen Willis

Karen Willis, has contributed in the analysis and to the interprettion of the findings and has contributed significantly in revising the manuscript and in approval of the final manuscript

Description of co-author's contribution (if applicable)
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Kristian Larsen, has contributed significantly in designing the study, including selection of methods and method development, and in the analysis and in interpretation of the findings
Kristian Larsen, has contributed significantly in revising the manuscript and in approval of the final manuscript

Description of co-author's contribution (if applicable)
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Ingrid Poulsen has contributed significantly in revising the manuscript and in approval of the final manuscript
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Description of co-author's contribution
Name of co-author: Karen Willis

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Description of co-author's contribution (if applicable)
Name of co-author: Kristian Larsen

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Description of co-author's contribution (if applicable)
Name of co-author: Ingrid Poulsen

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