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- an entrance to studying inequality in the Danish welfare state

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DOI (link to publication from Publisher):
10.54337/aau448601316

Publication date:
2021

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Bystrup, M. R. (2021). *Social Network Relations in Neurorehabilitation Trajectories: - an entrance to studying inequality in the Danish welfare state*. Aalborg Universitetsforlag. https://doi.org/10.54337/aau448601316

SOCIAL NETWORK RELATIONS IN NEUROREHABILITATION TRAJECTORIES

– AN ENTRANCE TO STUDYING INEQUALITY IN THE DANISH WELFARE STATE

BY
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DISSERTATION SUBMITTED 2021

AALBORG UNIVERSITY
DENMARK

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by

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Thesis submitted

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Dissertation submitted: May 2021

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PhD Series: Faculty of Humanities, Aalborg University

ISSN (online): 2246-123X
ISBN (online): 978-87-7210-941-1

Published by:
Aalborg University Press
Kroghstræde 3
DK – 9220 Aalborg Ø
Phone: +45 99407140
aauf@forlag.aau.dk
forlag.aau.dk

Printed in Denmark by Rosendahls, 2021

CV

Mette Ryssel Bystrup is a teacher, holds a master's degree in educational sociology, and is enrolled as a PhD student at Aalborg University, Department of Culture and Learning, Copenhagen, Denmark and affiliated with Hammel Neurorehabilitation Centre and University Research Clinic.

Her overall research topic concerns inequalities and marginalization in the Danish welfare state, wherein health and illness have represented the point of rotation when studying this phenomenon. Marginalization has been her focal point for the past 15 years and accounts for the common thread in her work with different target groups in various job contexts over that timespan.

She acquired practical experience with this topic during an anthropological-sociological study interviewing and observing marginalized people on the island of Langeland. Hereafter, she received practical and administrative experience with the topic by working in municipal administrative job positions (e.g. as a municipal health consultant managing health initiatives and at a municipal treatment centre for people with drug addiction) as well as working as a self-employed freelancer doing evaluation reports for various public institutions. Bourdieu has constituted a theoretical travel companion, providing her with a lens through which to approach and understand what has been experienced.

Throughout and parallel with her PhD study, the brain injured, as an empirical target group provides renewed and interesting perspectives to her exploration of inequalities and marginalization in the Danish welfare state in both a hospital as well as a municipal setting. She intends to further explore these topics in future studies.

ENGLISH SUMMARY

Inequalities in illness, service provision and outcomes are persistent (and, in some regards, increasing) even in Northern European welfare states. This is true despite these states' redistributive policies driven by the principle of free and equal rights to social and healthcare services which aim to prevent such inequalities. To a large extent, it is a mystery how these inequalities are produced during illness courses. Studying and explaining inequality in these Nordic contexts require us to consider the more hidden aspects of inequality. Inequality research often focuses on either framing structures (e.g. organizations) or socio-economic disparities; however, combining these approaches offers new perspectives.

The rehabilitation trajectories of young adults, age 15 to 30, with a severe acquired brain injury (sABI) provide a window for investigating the mechanisms behind inequality, as these trajectories involve multifaceted and long-term rehabilitation needs accommodated by various specialized rehabilitation services provided by different welfare state institutions across sectors and legislative regulations. In addition, because the age of 18 constitutes a juridical border, age-related limbo increases the complexity and number of institutions involved in these trajectories. This age-illness combination makes young adults with an sABI particularly vulnerable, as their transitional stage of life raises issues related to education, employment, family, and social life. Little is known about the dynamics of inequality throughout the rehabilitation process, including the time after discharge. In addition, the time spans in previous studies on ABI are short; some only contain single points in time, therefore overlooking the dynamics of inequality and the appurtenant institutional navigation and long-term conversion of capitals required by the afflicted families. As a key to exploring these inequalities, a specific focus is hereby placed on social network dynamics and the possibilities of converting this social capital to other capital forms in the rehabilitation process. However, social network relations might not only be crucial in acquiring rehabilitation services but also significantly impact aspects of social life, as social relations for chronic ill is linked to the extent of social participation and family engagement is known to be vital for community (re)integration for individuals with ABI.

These combined considerations led to the overall research question of the study:

How is inequality (re)produced in the rehabilitation trajectories of families with a young adult who has acquired a severe brain injury?

This question was approached from different analytical levels. A macro-level perspective analysing historical and political documents from a sociological field perspective provided an overview of the structures manifested and actualized in contemporary NR at meso- and micro-levels, as explored in the rest of the project. The design was longitudinal, following eight young injured adults and their families from before discharge at a HS rehabilitation hospital to 1½ years after discharge. In

addition, two pilot cases were followed from ½ year after discharge to 2½ years after discharge, serving as supplementary material. A multiple case study design was suitable for this in-depth exploration of the rehabilitation courses which involved multiple data sources (professional records, observations, interviews, focus-group interviews and surveys, including a name-generator list of significant social relations) and various perspectives (the young adults, the relatives and the professionals) converging in a triangulating fashion.

The initial and primary theoretical framework comprised the theories of Bourdieu for the study of reproductive structures in rehabilitation. However, the thesis also draws upon different scholars' reworks, refinements and new perspectives to empirically explore social capital and social network relations. A sociological theoretical framework concerning friendship was applied in combination with a social network analysis (SNA) methodology to capture, visualise and analyse social network relations and dynamics as well as explain the network processes in the families.

This theoretical and methodological framework has made it possible to study inequality in rehabilitation as a contextual, social and dynamic process combining underlying structures and individual life circumstances. This contributes with new perspectives to understand mechanism behind inequality, supplementing the epidemiological approach that currently dominates research on inequality in health and illness.

The study has materialized in four papers, all contributing to the overall findings and conclusion: Rehabilitation after an sABI is acquired entails institutionalization for a long period of time, whereby the focus historically and politically is placed on the individual and physical body due to its biomedical domination. This is despite the presence of multi- and interdisciplinarity in practice and an increased focus on other aspects of a patient's life; for example, relatives have recently been offered greater consideration. The arrangements during hospitalization and further specialization largely entail living in a social bubble during rehabilitation, with limited access to one's social relations from before the injury. This impacts a patient's ability to convert social relations to social capital, which is crucial for the acquisition of rehabilitation services and the navigation of the rehabilitation process. This is especially important for sABI patients, who undergo a highly demanding and complex rehabilitation process characterized by various agendas and 'rules of the game' due to the many different regimes (including cultures, logics and agendas) encountered, such as medicine, social affairs, education, occupation, economy and jurisdiction. In addition, the rehabilitation process offers unequal access to services (dependent on, e.g., age and regional or municipal belonging). The ability to navigate this process and overcome barriers was closely related to social class belonging, including possession and conversion of cultural health capital, social and bureaucratic capital, and the ability to match the doxas encountered in rehabilitation. But social relations are not only crucial in relation to the rehabilitation process; they might also be decisive for the long-term social life consequences of the injured patient, as they play a vital role in the (re-establishment) of everyday life and, hence, avoidance of social isolation.

This thesis suggests that ‘relatives’ must be considered more broadly, and that they must be widely prioritized and reconceptualized throughout the rehabilitation course. In this regard, rehabilitation institutions, including the representation of professionals, play a crucial role in patients’ engagement in social relations as well as in the impending risk that these relations will deteriorate over time. This is especially true for injured patients with more fragile social networks who need more support to maintain or even expand these networks than injured patients with more solid networks who can activate social support on their own. The social gap between injured patients might hereby increase throughout a rehabilitation course, reinforcing the more general inequalities in the Nordic welfare state.

DANSK RESUME

Uligheder i sygdom, ydelser og udfald er et vedvarende (og på nogle måder tilmed stigende) problem også i de nordiske velfærdsstater. Dette på trods af en omfordelingspolitik, der er drevet af princippet om gratis og lige rettigheder til sundheds- og sociale ydelser, der sigter mod at forhindre uligheder. I høj grad er det uklart, hvordan sådanne uligheder udmønter sig under sygdomsforløb. At studere og forklare ulighed i nordiske sammenhænge retter vores opmærksomhed mod mere skjulte aspekter af uligheden. Forskning i ulighed fokuserer ofte på enten rammesættende strukturer (f.eks. organisering) eller socioøkonomiske forskelle, men ved at kombinere de to åbnes der op for nye perspektiver.

Rehabiliteringsforløb for unge mellem 15 og 30 år med en svær erhvervet hjerneskade (sABI) udgør en åbning til at undersøge mekanismer bag ulighed, fordi det involverer forskelligartede og langsigtede rehabiliteringsbehov, der afføder en række specialiserede rehabiliteringstjenester leveret af forskellige velfærdsstatslige institutioner på tværs af sektorer og lovgivninger. Derudover øger det aldersmæssige limbo mellem barn og voksen med den juridiske grænse på 18 år kompleksiteten og antallet af involverede institutioner. Samtidig er unge en højt prioriteret aldersgruppe indenfor rehabilitering.

Alders-sygdomskombinationen bevirker, at unge med en sABI er særligt sårbare, hvor der rejses spørgsmål om uddannelse, job, familie og deres sociale liv. Viden om dynamikker indenfor ulighed gennem hele rehabiliteringsforløbet - inklusiv tiden efter udskrivelse - er begrænset. Derudover er det empiriske tidsrum i tidligere ABI-studier kort, hvor mange kun indeholder et enkelt nedslag, som forhindrer udforskningen af dynamikker over tid inklusiv navigering og konvertering af kapitaler blandt de ramte familier. Som en indgang til at udforske sådanne uligheder placeres et specifikt fokus på sociale netværksdynamikker og muligheden for at konvertere social kapital til andre kapitalformer i rehabiliteringsforløbet. Sociale netværksrelationer kan dog ikke kun være afgørende hvad angår erhvervelse af rehabiliteringsydelser, men også hvad angår sociale livsaspekter, da vi ved, at sociale relationer for kroniske syge er af afgørende betydning for (gen)integrering i samfundet.

Alt dette blev konverteret til afhandlingens overordnede forskningsspørgsmål:

Hvordan (re)produceres ulighed i rehabiliteringsforløb for familier med et ungt medlem, der har erhvervet en kompleks hjerneskade?

Dette spørgsmål blev tilgået fra forskellige analytiske niveauer. Et makroniveau, hvor historiske og politiske dokumenter blev analyseret fra et sociologisk feltperspektiv, gav et overblik over strukturer, der manifesteres og aktualiseres i nutidig neurorehabilitering (NR). Sådanne strukturer udforskes fra et meso- og mikroniveau i den resterende del af projektet. Designet var longitudinelt, og fulgte otte unge med svær ABI og deres familier fra før udskrivelse fra et højtspecialiseret

rehabiliteringshospital til 1½ år efter udskrivelsen. Derudover fungerede to pilotstudier som supplerende materiale, hvor to unge blev fulgt fra ½ år efter udskrivelse til 2 ½ år efter udskrivelsen. Et multipelt casestudie design var hensigtsmæssigt til at gennemføre en dybdegående undersøgelse af rehabiliteringsforløbene, der involverer flere datakilder (professionelle journaler, observationer, interviews, fokusgruppeinterviews og spørgeskemaer, herunder en navne-genereringsliste over betydningsfulde sociale relationer) og forskellige perspektiver (de unge, de pårørende og de professionelle), som alt sammen blev sammenholdt.

Bourdieus teorier og begreber udgjorde en indledende og primære teoretiske ramme til at undersøge reproduktive strukturer i rehabilitering. Men afhandlingen trækker også på forskellige forskeres videreudvikling og nuancering af teorierne samt nye perspektiver til at udforske social kapital og sociale netværksrelationer empirisk. Til at indfange, visualisere og analysere sociale netværksrelationer og dynamikker og til at forklare netværksprocesser i familierne blev en sociologisk teoretisk ramme om venskab kombineret med social netværksanalyse (SNA). Den teoretiske og metodiske ramme gjorde det muligt at undersøge ulighed i rehabilitering som en kontekstuel, social og dynamisk proces, der kombinerer underliggende strukturer og individuelle livsforhold. Dette bidrager med nye perspektiver til at forstå mekanismerne bag ulighed og supplerer den epidemiologiske tilgang, der dominerer forskningen om ulighed i sundhed og sygdom.

Undersøgelsen har materialiseret sig i fire artikler, der alle bidrager til den overordnede konklusion: Rehabilitering, når en sABI, erhverves indebærer lang tids institutionalisering, hvor fokus historisk og politisk set placeres på den individuelle og fysiske krop. Dette til trods for at rehabilitering i en nutidig kontekst er karakteriseret ved en multi- og tværfaglig praksis og en øget tildeling af opmærksomhed til andre livsaspekter, ligesom pårørende også gradvist er blevet tildelt en større opmærksomhed. Indlæggelsen og den videre rehabilitering indebærer i høj grad et liv i en social boble, hvor den unges adgang til deres sociale relationer fra før skaden er begrænsede. Dette påvirker muligheden for at konvertere sociale relationer til social kapital, som er af afgørende betydning for erhvervelse af rehabiliteringsydelser og for at navigere i rehabiliteringsforløbet. Dette gør sig især gældende for sABI-patienter, der gennemgår meget krævende og komplekse rehabiliteringsforløb, der er kendetegnet ved forskellige dagsordener og 'spilleregler' på grund af de mange forskellige regimer (herunder kulturer, logikker og dagsordener) de møder, så som medicin, sociale forhold, uddannelse, erhverv, økonomi og jurisdiktion. Derudover er rehabiliteringsprocessen karakteriseret ved ulige adgang til tjenester (afhængig af f.eks. alder, regionalt og kommunalt tilhørsforhold).

Dét at navigere denne proces og overkomme barrierer forbundet hermed var tæt forbundet med sociale klassetilhørsforhold, herunder besiddelse og konvertering af kulturel sundhedskapital, social og bureaukratisk kapital og muligheden for at matche de doxas, de mødte i rehabiliteringsforløbet. Men sociale relationer og forhold er ikke kun afgørende set i forhold til rehabiliteringsforløbet, men kan også være af betydning for langsigtede sociale livsforhold så som (genoprettelse) af et hverdagsliv og social isolation. Denne afhandling foreslår, at man betragter "pårørende" i en bred forståelse og som en dynamisk størrelse, der rekonceptualiseres gennem et rehabiliteringsforløb. I den henseende spiller rehabiliteringsinstitutionerne med repræsentation af fagprofessionelle en afgørende rolle ved inddragelsen af sociale relationer samt en betydning for at mindske risikoen for, social isolation. Dette er især tilfældet for tilskadekomne med mere skrøbelige sociale netværk, der har brug for støtte til at blive bevaret eller måske endda udvidet sammenlignet med tilskadekomne med et mere solidt netværk, der selv er i stand til at aktivere social støtte. Den sociale kløft kan således øges under et rehabiliteringsforløb og forstærke mere generelle uligheder i den nordiske velfærdsstat.

ACKNOWLEDGEMENTS

This PhD emerged from possibilities, curiosity and a constant need to take on challenges, and the supportive and inspiring people around me have made it possible. I therefore owe many people special thanks:

The families who agreed to be enrolled in my project and who let me into their lives at a very vulnerable time; I owe you a big thank you for your time, perspectives, and life stories in making this study possible. Many of you expressed this willingness out of the hope of helping others in the same situation. I will do my best throughout this thesis and all the other opportunities I get to communicate my message and call for reflection. I hope this invites for further discussion on how we can improve rehabilitation and the whole life situation for patients and their relatives.

Anette Lykke Hindhede for being my patient and supportive main supervisor who taught me important knowledge and strategies of academia. I am grateful for you sharing your expansive knowledge, your openness towards my ideas, the concrete feedback you always gave and your considerable ability to reduce complexity and hit the nail on the head. With you as my supervisor, I have always felt prioritized and in safe hands.

Kristian Larsen for being my inspiring teacher and supervisor and sparked my curiosity about the relational approach provided by Bourdieu. You have shared your knowledge, taught me how to transform the theories of Bourdieu into empirical studies, and contributed to my scientific habitus as an apprentice. This was the case in our study of marginalized people on Langeland, where we were let into the lives of people in an exposed situation, which made a major impression on both of us. Despite our uneven social position/professional relationship, I have always felt your confidence and respect for my person and perspectives. You have been a father-like figure in academia to me by believing in my skills, opening doors to interesting research milieus, and always approaching me as a whole person (including me as a private person). ‘Enhedsmøderne’, which you invited me into, has been a safe and supportive arena for many years, where new ideas, inspiring texts and interesting people have given new perspectives and energy to my study.

The Phlegethon network has been an essential source of inspiration from the beginning with its perspectives on welfare states, inequality and neurorehabilitation contributed by many institutions and researchers from both Norway and Denmark. Also, it has provided a safe arena for the discussion of the themes explored in the thesis with many competent researchers interested in the same topic and generously sharing their substantial knowledge. Phlegethon was also the research network where the project started, initiated by my encounter with Hanne Pallesen and Lena Aadal from Hammel Neurorehabilitation Center and University Research Clinic (from here referred to as Hammel Neurocenter), who eventually became my supervisors. I appreciate the two of you inviting me into the research unit in Hammel and your

support of me in starting my project and the initial funding. I also value the constant and enormous solicitude and support you have shown me throughout the whole journey and the space you have given me to do things in a way that was most suitable for me while finding my own feet in the process.

The research unit in Hammel under the leadership of Jørgen Feldbæk Nielsen has provided me with a network of warm and knowledgeable colleagues who continuously listened to the ‘peculiar‘ research I presented. Also, they let me in and made it possible to acquire important knowledge from the world of neurorehabilitation. In addition, to the youth mentors from Central Denmark Region and the group of professionals under the lead of Lærke Klitgaard and Helle Dybkjær, I would like to thank you for continuously showing interest in and supporting me and my project.

As part of my PhD study, I visited the Department of Political Science at Aarhus University. I would like to thank Gitte Sommer Harrits for taking me in and the Sociology Unit for letting me absorb from your vast accumulated knowledge.

Lately, the University of Aalborg and the Medical Humanities Research Group also created an inspiring, supportive and appreciated research milieu in which I could conduct the final stage of the PhD project.

I would like to extend a great thank-you to my PhD colleagues Rikke Guldager, Lone Falck Jørgensen and especially Helle Rønn Smidt, who followed me throughout the process, sharing triumphs and defeats on both a professional and personal level. You have been absolutely irreplaceable.

I would like to thank my parents and sister for their encouragement and belief in me no matter how high a mountain I climbed. Thanks also to Henrik for making this project possible by being there for our children when I was not present, giving me technical and financial support, as well as for your spirit of never giving up. And to my two children, Sigurd and Mie, for the life joy you always share and the support this has constituted, keeping my heart warm and my mind open for new developments and perspectives.

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READERS GUIDANCE

This article-based thesis consists of the wrapping of the whole study (termed ‘Kappe’ in Danish) followed by the four articles. In Chapter 1, I start by setting the scene with my first experiences with neurorehabilitation (hereafter NR) that generated the initial curiosity and wondering which became the basis for the construction of my research questions presented hereafter. This is followed by the scientific placement of my research project and me as the researcher (a socio-analysis), providing the reader with knowledge of the lenses I used when constructing the research object. Chapter 2 creates an overview of the papers and the existing literature on inequality in NR followed by a clarification of knowledge gaps. Chapter 3 consists of reflections on the theoretical framework. Chapter 4 is an overview of the design, methodological approaches and data construction. Chapter 5 explores urgent ethical concerns. Chapter 6 consists of reflection, discussion and perspectivism on the four papers. Chapter 7 is the conclusion of the thesis and presents the estimated implications for practice. Chapter 8 is a perspectivation of the findings, including future possible research paths. Hereafter the articles follows, where only paper 1 and paper 2 are included in the official printed version.

LIST OF PAPERS

This thesis includes the following papers:

Paper 1

Bystrup, M. R., Larsen, K., Hindhede, A. L., Pallesen, H., Aadal, L., & Feiring, M. (2018). Outline of a History of Neurorehabilitation in Denmark–a Sociological Perspective. *Praktiske Grunde 3-4*.

Paper 2

Bystrup, M. R. & Hindhede, A. L. (2019). Conversion of Social Capital in the Rehabilitation Process of Adolescents Following an Acquired Brain Injury. In *New Dynamics of Disability and Rehabilitation* (pp. 195-223). Palgrave Macmillan. **https://doi.org/10.1007/978-981-13-7346-6_9**

Paper 3

Bystrup, M. R., Hindhede, A. L., Pallesen, H., Aadal, L & Larsen, K. (forthcoming) Unequal Neurorehabilitation Trajectories – A Longitudinal Case Study Merging Framing Field and State Structures with Families' Social Class Positioning (Submitted)

Paper 4

Bystrup, M. R., Aadal, L, Pallesen, H., Larsen, K., & Hindhede, A. L. (forthcoming) 'Who are Relatives? – Perceptions of Relatives during the Rehabilitation of Young Adults with a Severe Acquired Brain Injury' (In review)

Note: Paper 3 and paper 4 are not included in the official printed version due to the process of submission to journals.

CHAPTER 1. BACKGROUND INCLUDING CONTEXT AND RESEARCH QUESTIONS

To set the scene for this thesis, I open with a practical observation made at my first encounter with NR. I was invited to a residential rehabilitation institution to shadow professionals in their work with brain-injured residents. I noticed that some of these patients were surrounded by friends and family on a daily basis, while others were alone for most of the time – except for the company of the professionals or other residents. This seemed a stark contrast to the pictures of their former social lives which hung on their walls and showed them surrounded by families and friends, celebrating a win with their sports team, attending a wedding, fishing with a father, etc. It appeared that some of the injured came from other parts of the country, often several hours' drive away, making it difficult for friends and families to visit. This distance was in some cases compensated by phone calls between the parents and professionals to provide information on how their son/daughter was doing. In other families, the distance was overcome by a parent lodging nearby or even at a mattress in the 'flat' of the injured patient. I noticed that the family and friends who were physically present on a regular basis had a different engagement with the life of the injured. They also had a different form of communication with professionals, whereby daily care, rehabilitation and 'leisure activities' (e.g. going for a drive) were naturally coordinated and adjusted to the patient's energy levels. In comparison, the friends and family living far away from the injured instead appeared as 'visitors' on the side-line or took part in 'invented' activities arranged by the professionals. However, such interaction between professionals, relatives and the injured patient is not always easy, as shown in the following quotations:

> 'the parents were in the beginning very participatory in the training but has now been asked not to participate because it interrupts [the patient] (they are very speaking – including negative comments)'
>
> and
>
> 'The undersigned expects them [parents] to respect, that we want peace to work with [the patient] and that they might need to leave the flat if necessary when training'.

After a long drive, when relatives were finally able to visit, these visits were often long and exhausting for the patient: '[name of patient] endurance vary a lot. He is most often experienced very tired in the days after weekends because of increased social activity with many visitors'.

This observation made me realize that our rehabilitation arrangement affects and changes the social life situation of injured patients and impedes a natural upholding of their former social life relations. But for some, this change is more radical than for others. I also detected instances in which differences in the appearance of friends and families affected the support available for injured patients as well as their experiences with professionals and the rehabilitation process. Thus, I started wondering whether relatives constitute a brick in the puzzle of understanding inequality in the welfare state, both directly linked to the rehabilitation services received by the injured patient and as indirect consequences in the broader life perspective of the patient.

1.1. PURPOSE AND RESEARCH QUESTIONS

Inequalities in illness, service provision and outcome are well documented, even in the universal Nordic welfare state. However, it largely remains a puzzle how this inequality is (re)produced despite many political attempts to reduce it. The overall purpose of the thesis is hereby to contribute to the body of research exploring the mechanisms behind inequality in the Danish welfare state from an empirical approach to understand how this inequality takes place in practice. The rehabilitation of people with a severe acquired brain injury (sABI) provides a window for investigating this inequality because it involves multifaceted and long-term rehabilitation needs (Benedictus et al., 2010) accommodated by a variety of specialized rehabilitation services provided by different welfare state institutions across sectors and legislative regulations. This has resulted in the overall research question:

How is inequality (re)produced in the rehabilitation trajectories of families with a young adult who has acquired a severe brain injury?

This is further concretized in the following four work questions:

- *How can NR be understood from a sociological field perspective in order to illustrate framing structures and dominant positions shaping the practices? (Primarily answered in paper 1).*

- *How and why do trajectories after an ABI vary among social classes and which resources are required when families are struggling with serious injuries in and between different institutions? (Primarily answered in paper 3)*

- *How is social capital invested and converted during the process of rehabilitation and how can this be used to explain inequality? (Primarily answered in paper 2 (and paper 4))*

- *Who is considered a 'relative' during rehabilitation and how can a sociological theorizing of 'relatives' provide an entrance to study inequalities? (Primarily answered in paper 4)*

1.2. FRAMING THE RESEARCHER AND THE RESEARCH PROJECT

I consider myself as a researcher, my theoretical inspirations, and the empirical material as an interactive whole when constructing the research object (Alvesson & Kärreman, 2005). This is in contrast to an approach that studies a phenomenon as an isolated object with the researcher being value-neutral and a philosophy of science as an endeavour that objectively mirrors what can be seen; thus, my study employs a novel approach to the world of NR where a positioning of me as a researcher and the research project is inevitably since the approach to the research object, including the interpretation of the data material, is strongly affected by the perceptions of the researcher (Bourdieu & Wacquant, 1992; Hansen & Larsen, 2015).

The birth of this PhD thesis has been long and has faced many obstacles, but, as I do believe, there was a purpose to all this. Time and detours were needed to acquire, comprehend and convert the knowledge into a clear message, both for myself and for the recipients. The many obstacles have shaped the process and product and have forced me to constantly develop, both as a researcher and as a human being. One of these obstacles is my parallel journey of being a parent to a child who do not fit into society's comprehension of being 'normal' and hence entered the psychiatric system. This experience has provided me with indispensable knowledge on urgent topics that were also expressed by the families I interviewed, i.e. by being a 'relative' and finding my way through the welfare system while simultaneously trying to keep afloat by holding onto work, family and friends and the whole meaning of life. Of course, this is not at all comparable to the strength, the encompassing character and the larger life implications of those who are close family members to a young person with an sABI. However, it has provided me with practical knowledge on investing and converting capitals when an 'illness' occurs. This is an example of a life experience that shaped my construction of the research object. Such self-reflexive work, I believe, is necessary to establish scientific knowledge and overcome what might seem obvious (Bourdieu, 1999: 613-615; Bourdieu, 2003; Brummans, 2015).

In this section, I therefore present an objectivation of both my historical and contemporary universe informing my research interest and work. This entails my social origin, position and trajectory in academia as well as NR. This objectivation visualizes the relationship between me as a researcher and the researched and describes what has shaped my outlook (Bourdieu, 2003).

My entrance to the world of academia has not been through the front door, as noted by my predefencer, Annick Prieur. I come from a working-class family with a father who, through hard work and persistence, made it to the top of Danish business life during my childhood. He has constituted a role model to me and this, together with my parents' endless support and belief in my skills, made me continue climbing the educational ladder. I started with a teacher's education, which triggered my interests and values surrounding equality (as strongly manifested in the Danish school law, with its values of being free of charge, its principles of inclusion etc.). In addition, it gave me experience in being a professional with the Danish welfare state as my overall employer, as reflected in both the organization and content of the practice. From this experience, I was able to draw parallels when working with my empirical material. For example, based on my previous experience holding meetings at schools concerning pupils with special pedagogical needs, I found there were parallels between these meeting and the intersectorial discharge meetings observed in this PhD study. This socializing to become a teacher was also my first brief encounter with the sociologist Pierre Bourdieu. This led me to start my master's education in educational sociology, providing me with a toolbox of sociological perspectives and an academic schooling that shaped my dispositions. I ultimately wrote my thesis on inequality in sports, studied from a Bourdieuan perspective. Inequality and marginalized life positions were perspectives that I further explored from a practical and interventional perspective through a normative work approach in the following five years in job positions under municipalities (e.g. as a municipal health consultant managing health initiatives). These perspectives and approaches have become deposited in my habitus and are reflected in my research position as a strong wish to make a difference for practice. I am aware that such agendas (knowledge production vs normative, practical intervention) are to a large extent contradictory, and time and reflections have been necessary to balance this.

An invitation from Hammel Neurocenter to study the trajectories of young adults initiated this project and defined the age group, the severity of the ABI and the regional demarcation. This invitation also included an inclusion to the research unit of Hammel Neurocenter, and hence, my entrance into the world of NR. This multi- and interdisciplinary research unit is a world that, as I soon experienced, had a prioritising of the injured body and its functioning. This tradition also entails a strong focus on the newest available knowledge and a research hierarchy with RCT studies considered the golden standard (Krogstrup, 2018). This is in contrast to my inspiration in a praxeological research tradition, which is characterized by a valuing of history and, to a large extent, occupied by structures lying behind what is visible. This outside perspective put me in a strong position to maintain a distance to the research phenomenon studied allowing me to generate an epistemological break with the common-sense perceptions naturalized and being unquestioned by insiders in NR (Prieur, 2002).

As a result of my non-academic habitus together with no fixed PhD agreement from day one, the initial period of the study was characterized by trial and error with the design and protocol as well as attempts to raise funding. This included the ongoing work of acquiring a scientific habitus (Larsen, 2021) entailing the development of a practical mastering (Atkinson, 2012). In hindsight, I consider this initial period to have been a necessary learning process to be able to demystify the world I entered, to strengthen my intuition[1] and to build up experience and the courage to be critical. Nevertheless, it has pervaded the final design and product, rendering it easy to identify unnecessary detours and what could have been done differently.

My entry into NR as a foreigner is, in some regards, comparable to the families' entry into NR due to the immediate need to decode the practices naturalized by insiders. This has created common questionings and reflections between me and the families during the interviews, such as when a mother criticized the lack of emotional help when her child was hospitalized with an ABI:

> 'I think it is scandalous, that a place like [HS-hospital] who only receive people who have been in deep life crisis emerging suddenly, they don't have one single crisis-psychologist. That is, they don't have one person who can talk to people about the situations they have encountered and help them'.

To maintain scientific distance despite such social proximity, constant reflexive work became my travelling companion throughout the project.

My starting position among professionals and researchers in NR was relatively low. This was because I lacked an acknowledged health care education and conducted my research using qualitative research methods, thus diverging from a research hierarchy that favoured RCT studies with objectifiable and measurable outcomes (Krogstrup, 2018). An example of my subordinate position, which resulted in my not being considered an important 'player', became apparent when I was to observe at one of the discharge meetings yet the department team forgot to advise me thereof. Nevertheless, I continuously gained broader approval from NR professionals due to my study of a topic (social life issues) with an increased political urgency (e.g. National Board of Health, 2011: 120), from a perspective (the injured and relatives) that is becoming increasingly prioritized (Bonfils, 2006) and represents a research discipline that is relatively 'new' and considered by some in NR as providing new insights. In addition, my affiliation with Hammel Neurocenter served as a seal of approval for my project heightening me and my position outside this institutional setting, as this institution is high-positioned in NR (e.g. Newsweek, 2021). Ultimately, this allowed me to gain access to a broad audience and various invitations to present my results, hence heightening my position in NR.

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[1] Also, Bourdieu had a strong belief in intuition and considered this practical and acquired knowledge (not inherited or magical skills) (Prieur, 2002: 115).

CHAPTER 2. INTRODUCTION

2.1. OVERVIEW OF THE PAPERS

My response to the research questions has materialized in four papers, which are briefly overviewed in the following table. A brief summary of each paper, the linkage between each paper and the overall research question, and the reflections developed during or after the papers were written will follow in chapter 6.

	Paper 1	**Paper 2**	**Paper 3**	**Paper 4**
Title	*'Outline of the History of Neurorehabilitation in Denmark – A Sociological Perspective'*	*'Conversion of Social Capital in the Rehabilitation Process of Adolescents following an Acquired Brain Injury'*	*'Unequal Neurorehabilitation Trajectories – A Longitudinal Case Study Merging Framing Field and State Structures with Families' Social Class Positioning'*	*'Who are Relatives? – Perceptions of Relatives during the Rehabilitation of Young Adults with a Severe Acquired Brain Injury'*
Journal / status	Praktiske Grunde	Book chapter in '*New Dynamics of Disability and Rehabilitation: Inter-disciplinary Perspectives'*	Submitted	In review
Analytical Level	Macro	Micro	Meso and micro	Meso and micro

Aim	To unravel the genesis and history of NR in Denmark to understand its present structure and practices.	To investigate how social capital is invested and converted during rehabilitation	To explore how and why rehabilitation trajectories after ABI vary among social classes?	To explore the perception of 'relatives' during the rehabilitation of a severe brain injury (sABI)
Theoretical inspiration	Pierre Bourdieu's concept of field	Alejandro Portes' presentation of social capital	Pierre Bourdieu's theory of field, capitals and doxa	Pahl and Spencers' theory on personal communities and PRISM[2]
Empirical Design	A historical review study of historical and political documents	A qualitative study (observations, records, focus-group interviews, interviews, surveys)	A qualitative and longitudinal study (observations, records, focus-group interviews, interviews surveys)	A qualitative and longitudinal study (records, focus-group interviews, interviews, surveys)
Results	Viewed from a field perspective, NR is a multi- or interdisciplinary practice characterized by heterogeneity, although with growing homogeneity in clinical practice with an underlying	Families with a strong, closed family structure were the most successful at transforming their capitals to rehabilitation assets, in contrast to the small and weak family structure and	The rehabilitation process after sABI consists of unequal accessibility to services and includes various agendas and rules of the game. Navigating this process and overcoming barriers was closely related	Social relations engaged as relatives are to a large extent connected to the perceptions of professionals and the patient's relatives. This possibly impacts the social support available for the young adult, who initially

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[2] PRISM is an abbreviation for personal relations in the social mind

	domination of a biomedical doxa.	the split family structure.	to social class belonging.	had a much larger personal community.

Table 1: *Overview of papers included in the PhD thesis*

2.1.1. ABSTRACT OF THE PAPERS

A brief summary of each of the four papers, the linkage between them and the connection to the overall research question will be presented in the following. I start by setting the scene using a macro-level perspective, including a historical and political exploration of NR (paper 1). The following three papers are primarily based on my own constructed empirical data material, moving to meso- and micro-level perspectives that explore social capital's transformability to symbolic capital in NR (paper 1 and 4). Bridging this, paper 3 contributes with an empirical exploration of NR trajectories from the meso and micro perspectives.

2.1.1.1 Paper 1

This first paper, with the title: *'Outline of the history of neurorehabilitation in Denmark – a sociological perspective'* (Bystrup et al., 2018), provides a macro-level framework to grasp and encompass structures manifested and actualized in social life at a micro level, as explored in the subsequent papers (paper 2, 3 and 4). A historical analysis is an unavoidable step to approach these structures (Bourdieu & Wacquant, 1992: 90). I focus on historical and political power relations structuring NR in Denmark in past decades as well as in the present. Hereby, I create an overview of the agenda set when an ABI occurs. The methodological approach is inspired by a document review strategy of historical sources and political documents. Instead of conducting a conventional historical analysis that presents events in a linear progression, I focused on struggles within NR and worked to apply this knowledge to explain present truisms. This process enabled me to identify and visualize the power structures among positions at macro and meso levels by identifying differences and struggles as the principle for generating internal dynamics in NR. I find that NR has undergone substantial transformations since the 1970s. Overall, my analysis showed that NR is a multi- and interdisciplinary practice characterized by heterogeneity, although with growing homogeneity in clinical practice due to an increased number of NR institutions and recent political guidelines prompting a formalization of treatments. Despite the increased power of psycho-social and comprehensive approaches, biomedical knowledge is still dominant and reflected in doxa, outliving its power through its alliance with political institutions. I argue that what NR is today, with its organization, practices, logics etc., is the outcome of controversies on knowledge, hierarchy and prestige among professionals throughout the years, which has resulted in a domination of biomedical knowledge embedded in logics and practices.

2.1.1.2 Paper 2

The book chapter *'Conversion of Social Capital in the Rehabilitation Process of Adolescents following an Acquired Brain Injury'* (Bystrup & Hindhede, 2019) contributes to a body of collaborative work on transitions within rehabilitation in the context of the welfare state and its changing role. This chapter has a direct link to paper 1 in order to explore the interrelatedness between field, habitus and capital in the concrete encounter between patients/relatives and NR. Hereby, I empirically explored how capital is invested and converted in NR by focusing on and drawing on theories of social capital. I investigate, through observations in a negotiating setting (discharge meetings) and medical records combined with interviews with the families, how intangible, non-material assets in the form of the family connections of the relatives of young people with an ABI activate services and 'goods'. I draw on Portes' (1998; 2000) expounding of the concept of social capital, which nuances, extends and gathers many of the thoughts originally recorded by Bourdieu. This theoretical starting point is combined with an SNA approach that enables me to map the social relations of the relatives to create an overview of relations that can be activated. I find that families with a strong, closed family structure have an advantage in transforming resources in the rehabilitation process, for example, due to their collaboration with professionals. This family structure is characterized by resources being concentrated in close, cooperating family members and subsequently transformed into cultural capital in the rehabilitation process, reaping greater benefits in terms of advantages, preferential treatment or additional services from the welfare state. In contrast, the small and weak family structure and the split family structure are the least beneficial in the rehabilitation processes. These network structures were associated with a low degree of negotiation and cooperation between the family and service professionals and left the families with little influence on the rehabilitation process and their own life situation.

2.1.1.3 Paper 3

Paper 3 is titled *'Unequal Neurorehabilitation Trajectories – A Longitudinal Case Study Merging Framing Field and State Structures with Families' Social Class Positioning'.* The paper builds on the findings of paper 1, with its macro-level perspective used as a framework to operationalize and interpret the empirical meso- and micro-level findings of this paper. To approach this paper, I empirically explored the brain injury trajectories of severely injured young adults using a case study design. This study provides a window into investigating the underlying mechanisms of inequality through multifaceted, long-term rehabilitation trajectories across sectors and legislative regulations. My starting point was asking how and why rehabilitation courses after ABI vary among social classes. Grounding our research in Bourdieu's theories, we explore inequality by combining framing structures with a socio-economic perspective of the young adults. In addition, the bureaucratic state as a meta power field regulating the fields at a distance through policies, legislation and value and exchange rate of the capitals setting is included in the interpretation of the empirical material. A longitudinal and qualitative case study design encompassing professional records, observations, and interviews enabled me to construct the families' trajectories during the process of rehabilitation. My Bourdieuan theoretical framework led my analytical attention to doxas, capital conversion and struggles throughout rehabilitation. I found that the rehabilitation process after an sABI offers patients unequal access to services (dependent on e.g. age, regional and municipal belongings) and includes various agendas and rules of the game due to the many different regimes (including cultures, logics and agendas) encountered, such as medicine, social work, education, occupation, economy and jurisdiction (see figure 1). The ability to navigate this process and overcome barriers was closely related to social class belonging, including possession and conversion of cultural health capital (CHC), social and bureaucratic capital, and the ability to match the doxas encountered in rehabilitation. The level of economic capital possessed by the families seem less influential, which might be explained by the extensiveness of the welfare state providing rehabilitation services free of charge. The disparities in capital volume and composition were reflected in the patients' rehabilitation trajectories, characterized by continuity on the one hand and extreme and broken trajectories on the other. I conclude that despite the welfare state's intentions to strive for equality, the access to rehabilitation services is unequal and is further reinforced by unequal capital possession among immanent social class structures all impacting rehabilitation trajectories. I end the paper by encouraging further discussion of how professionals might respond to these inequalities by supporting families with limited possession of capital.

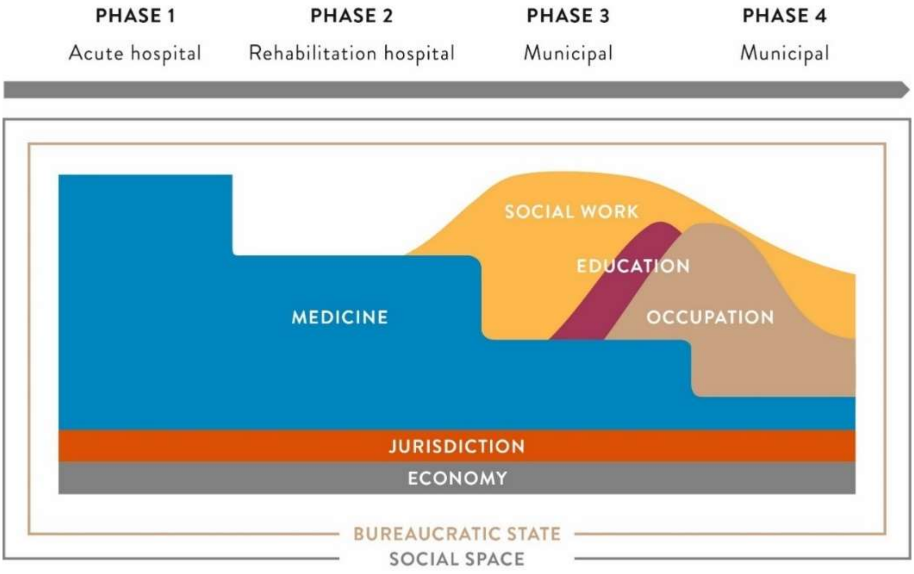

Figure 1: *Regimes encountered during rehabilitation*

2.1.1.4 Paper 4

Paper 4 *'Who are relatives? – Perceptions of relatives during the rehabilitation of young adults with an acquired severe brain injury'*. This paper explores social capital as studied in paper 2 by digging further into the definition and investigation of 'relatives'. This merges with the larger discussion on increased patient and relative involvement in Western countries' healthcare systems. The paper has been submitted to an international journal with an ongoing conversation on rehabilitation and the role of relatives on social life and hence community re-integration. The paper aims to examine which people are engaged as relatives in the rehabilitation of an sABI and compare this with the young adult's own perception of their social network. The longitudinal and qualitative design enables me to explore such perceptions and engagement of relatives throughout a rehabilitation trajectory from three different perspectives: those of the professionals, the closest relatives and the injured young adult. I apply a sociological theoretical framework that broadly considers friendship, enabling me to reposition relatives and social network relations in a broader and renewed understanding, thereby breaking with traditional perceptions in the social minds. SNA methodology is used to capture, visualize and analyse the young adults' perceptions of their significant social relations. I find that the activation of network ties during the rehabilitation process is not merely based on the adult's perception of their close network ties but rather is decided by professionals and parents. These decisions acknowledge a limited number of social relations, with a prioritizing of biological and juridical ties, and might be linked to the reduced social support available for the young adult in the long run, who initially had a much larger 'personal community'. A potential reduction of the young adult's larger social network thereby negatively impacts the size and strength of their personal community, increasing the risk of social isolation. I hereby conclude that rehabilitation institutions play a decisive role in individuals' ability to maintain a social network, even after rehabilitation. In addition, I suggest a professional rethinking of who 'relatives' are as well as a consideration of these ties as dynamic. The aim is to distribute the care burden and to preserve long-term social relations in the life of the young adult.

2.2. ENCIRCLING MY RESEARCH OBJECT - AN OVERVIEW OF THE EXISTING LITERATURE[3]

In this section, I encircle my research object through a brief historicization of (neuro)rehabilitation, a presentation of the target group studied, a contextualization and organization of contemporary NR as well as the existing literature on inequality in NR.

Existing inequalities regarding health care and its service provision and outcomes have been highlighted on a global scale (ESS, 2016; OECD, 2019; WHO, 2010; WHO, 2019). They are also common, and even increasing, in the Nordic welfare states despite their longstanding social democratic tradition of the universal provision of economic and social rights via redistributive policies aimed at preventing health inequality (Bambra, 2012; Diderichsen et al., 2011; Navarro et al., 2003; Navarro et al., 2006). Within the Danish welfare state, in particular, this universalism is a result of several hundred years of evolution, albeit with a significant expansion from the 1960s onward with the entry of women into the labour market. Caring for the sick, children and the elderly was hereafter taken over by professionals and thus institutionalized (Vallgårda, 2003). In Denmark's health care legislation (Ministry of Health, 2016), this universalism is reflected in an overall proclamation of easy and equal access to health care services for all inhabitants regardless of income. Thus, it is to a large extent a puzzle as to how these inequalities are produced in illness courses (Kamper-Jørgensen & Rasmussen, 2008).

Studying and explaining inequality in such a Nordic context makes an important contribution to the overall discussion on inequality by directing our attention to aspects that are more hidden than e.g. economic factors (e.g., private insurances, prestigious institutions and services affordable only to privileged groups of society)

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[3] For technicalities on how the systematic literature search was conducted, I refer to appendix A

(e.g. Collyer, 2018; Gengler, 2014) or choices about public or private health care services when navigating the healthcare maze (Willis et al., 2016).

NR of young adults[4] with sABI provides a suitable context for investigating the underlying mechanisms of inequality due to critical transitions and disruptions, as pinpointed by Harsløf et al. (2019). ABI is a diagnosis that appears abruptly and is caused by accidents, violence, illness or infections (Danish Health Authority, 2020); it is a predominant cause of death and disability among young adults worldwide (WHO, 2006). Every year in Denmark, approximately 1,200 adolescents aged between 15 and 30 suffer an sABI that requires hospitalization (Bakmann et al., 2019; Tibæk et al., 2017). The condition implies both cognitive and sensory-motor impairments, thereby impacting most aspects of daily life and requiring a multifaceted and long-term rehabilitation process (Benedictus et al., 2010). As adolescents are at an especially vulnerable life stage, they often face unique challenges when afflicted with an sABI (Bakmann et al., 2019; Doser et al., 2018). Thus, efforts are made to rehabilitate and establish a new everyday life that is supported by the welfare state.

Contemporary principal issues on rehabilitation in Europe date back to the First World War (Stiker, 1997). A large number of injured soldiers needed to be restored through normalization and integration, breaking with the previous practice of disregarding them. Hereby, new cultural and social perspectives were established. Following this period, disability and rehabilitation have developed through categorization, institutionalization, organization, a variety of approaches and a political prioritization (as e.g. shown in paper 1). Rehabilitation services across medicine and social services became a cornerstone of the universal welfare state in Northern Europe after the Second World War (Harsløf et al., 2019). This was also when the first tentative attempts were made to develop so-called holistic theories and contributions to rehabilitation programmes (Goldstein, 1995). Further developments hereof came from scholars in the USA, Switzerland, and Germany, who started applying therapeutic methods based on neuropsychology and pedagogy which challenged the biomedical approach (Ben-Yishay et al., 1987; Løvschal Nielsen, 2004; Luria, 1980). Since then, there has been an increasing acknowledgement of the need to consider rehabilitation through a comprehensive approach, including consideration of the family environment, to achieve better rehabilitation progress and a better outcome. In Denmark, rehabilitation is framed by the white book[5] (Marselisborg Centre, 2004) based on the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The ICF is promoted as a biopsychosocial model aiming to unite

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[4] The terms 'adolescents' and later 'young adults' are used for the target group of this thesis. These refer to a person's age and the appurtenant life sphere and is less connected to a certain context (including the culture and norms characterizing this), which is the case for alternative concepts, such as 'patients' used in a hospital/medical context, which draws our attention to the illness and deficits (as implicit in the system of diagnosis and pathological focus), or the term 'citizen', 'client' or (service) 'users', as used in a municipal context.

[5] A new white is forthcoming in September 2021

biological, psychological, and social approaches and thereby create a more composite understanding of illness and disability (WHO, 2002). This biopsychosocial model of illness is also highlighted in effective rehabilitation from a contemporary perspective (Wade, 2020). Such an approach entails a crossing of legislative sectors; according to the inter-ministerial guidance on municipal rehabilitation, this primarily involves health, social, occupational and educational legislation (Ministry of Interior and Health, Ministry of Social Affairs, Ministry of Occupation and Ministry of Education, 2011).

In Danish health care, there are four phases for the treatment and rehabilitation following an sABI: two hospitalized phases and two municipalized phases (Danish Health Authority, 2011a). Highly specialized rehabilitation (HS rehabilitation) is provided by two hospitals, which cover the whole country. Subsequently, for further rehabilitation, the patients transfer to a regional hospital or one in their local municipality (Danish Health Authority, 2011a). Although national standards exist, the rehabilitation services provided by the various municipalities vary; they can be short term, long term or maintaining (National Audit Office of Denmark, 2016). There are further variations in the quality and intensity e.g. according to the municipality's size and geography and how many local experts it has. Nevertheless, municipalities tend to draw on their own services (Danish Regions, 2011; National Audit Office of Denmark, 2016), which overall leads to varying results in terms of the rehabilitation outcome (Lekander et al., 2017). The transitions between the phases of rehabilitation usually imply moving to a lower level of expertise and intensity (Højbjerg et al., 2019). Patients also enter a different legislative system when they turn 18, meaning that a different set of municipal professionals and departments take charge of the rehabilitation process. Clear legislative boundaries exist between the different legislative systems, and the rights and practices informing a patient's rehabilitation change as they reach adulthood.

Furthermore, variations have been reported internationally in how patients with an mABi (moderate acquired brain injury) and sABI are referred and/or offered access to treatment and rehabilitation (Cnossen et al., 2017; Lynch et al., 2017). For example, patient age is a factor, with younger patients receiving priority access (Cnossen et al., 2017; Hakkennes et al., 2012), leading to higher HS rehabilitation rates (Odgaard et al 2015) and more direct transfers between acute care settings and specialized rehabilitation (Sveen et al., 2016). However, such epidemiological research only offers limited in-depth insight into the factors driving these inequalities.

Studies on inequalities in NR tend to highlight individual attributes or dimensions, including racial and ethnic factors (Meagher et al., 2015), gender (Mikolić et al., 2021), socio-economic disparities (K. K. Andersen et al., 2014; Haider et al., 2013; Marshall et al., 2015; Mikolić et al., 2021; Nirula et al., 2009; Van den Bos et al., 2002) and differences in economic resources (including insurance policies) (Alban et al., 2010) and regional variations (Tay & Wong, 2018). In addition, such inequalities have been closely linked to the patient's relatives (Foster et al., 2012; Lynch et al., 2015), family functioning (Sander et al., 2002) and neighbourhood characteristics

(Corrigan & Bogner, 2008). However, health care inequalities are better examined as relationally bound phenomena that take into consideration socio-economic differences in relations combined with the framing structures of field (Veenstra & Burnett, 2014). Few existing empirical studies convert these theoretical ideas in the field of ABI. Guldager et al. (2018) is an example of one of the few studies. They highlight field-specific capital comprising those unique cultural resources that can be mobilized to optimize rehabilitation while hospitalised. However, there is little knowledge about how these resources can be combined with framing structures to benefit the rehabilitation process as a whole, extending to the post-hospitalization period. Furthermore, most of the identified studies on inequality in the context of ABI cover relatively brief time spans, with some offering only single picks. Hence, there is a gap in the empirical knowledge that demands longitudinal research to explore the complexities of inequality in health care the developments and transformations in long-term rehabilitation processes of rehabilitation and how these lead to changes in the life of the injured patients and their families.

The Danish health care system has recognized the need to involve patients' relatives in decision-making and rehabilitation, with one of the aims being a reduction in inequality (Ministry of Health and Prevention 2014). This family involvement and engagement is significantly linked to improved outcomes as well as community integration for patients with an ABI (Batchos et al., 2018; Foster et al., 2012; Gagnon et al., 2015; Jones et al., 2011; Langagergaard et al., 2011; Rauch & Ferry, 2001; Sander et al., 2002). For example, a recent study on TBI patients in Denmark demonstrated that family caregivers are more effective than health care professionals at navigating the barriers and negotiations that exist even in rehabilitation services to which patients are already entitled (Graff et al., 2018)

Family members play a particularly important supportive role for patients with an ABI (Gagnon et al., 2015), representing a valuable source of information for health care professionals, as they can provide information on the patients' background (Danish Health Authority and National Board of Social Services, 2018). Furthermore, they are vital in shaping how the patient perceives and addresses their ABI (Reed et al., 2011). Thus, and according to Haines (2018), family members are an underutilized resource in the rehabilitation process of critically ill patients. However, the nature and severity of the ABI can lead to a heavy burden on family caregivers (Doser & Norup, 2016; Manskow, 2017). A Danish study on relatives of patients (not related to any specific illness category) who were also on the labour market showed that they considered helping a joy (82%) but also a burden (32%) (KMD analyse, 2018); whether helping patients becomes a burden has been linked to the number of hours relatives spend on caregiving (KMD analyse, 2018; van Campen et al., 2013). Nevertheless, many relatives to people with a serious illness wish to be involved to a larger extent than they are (National Health Authority, 2012). When patients are cared for by relatives, and therefore increasingly dependent on their families (Brzuzy & Speziale, 1997), problems may arise because for individuals living with a disability. Social relations in a broader sense are closely linked to both the disabled individual's perceived quality of life and the extent of their social participation (Jespersen et al., 2019). Patients with severe traumatic brain injuries (sTBI) are especially likely to experience decreased social networks, less social support, and reduced possibilities to build new social contacts (Sander & Struchen, 2011).

Although a number of studies have underlined the importance of family engagement in the rehabilitation trajectory, it has been difficult to identify a common terminology[6], e.g. who constitutes these social relations, and to determine which relationships play a significant role in the perceptions of relations to be engaged. Both political documents and the literature include relatively few persons in this category, often considering only spouses, parents and children and, to a far lesser extent, siblings, friends, colleagues and others. In this process, family relations are often emphasized, thereby following prevalent policies that point to a shared sense of obligation of the family, even in cases of chronic illnesses (Karp & Watts-Roy, 1999). These policies are generally based on dominant ideology among the public that promotes the perception of the caring family, which disregards the adverse consequences if a family relationship contains distrust, domination, molestation or criticism (Heaney & Israel, 2008). Based on the research by Heaney and Israel (2008), several types of relations can provide social support, yet a diversity among these remains key to good health (Stansfeld, 1999).

To summarize the knowledge gaps identified during the systematic literature search (see appendix A on technicalities) prompting this overview:

- Little is known about the dynamics of inequality throughout the rehabilitation process, including the time after discharge. In addition, the time spans in the above-mentioned studies on ABI are short; some only contain single picks.
- Inequality research often focuses on either the framing structures (e.g. organization) or socio-economic disparities, and studies combining the two are scarce.
- The literature is dominated by the consideration of family as relations, overlooking the exploration of other social relations as a potential source of social support.

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[6] The literature (and political documents) uses concepts such as (informal or non-professional) caregivers, relatives, family, carers, next of kin, service users and joint carers.

CHAPTER 3. REFLECTIONS ON THE THEORETICAL FRAMEWORK

In the following section, I reflect upon the central concepts used in this thesis. An eclectic approach was taken in order to accommodate new visions of the world, as argued by Køppe (1990) and based on the acknowledgement of the fundamental interconnectedness between phenomena. In addition, the complexity of the research object exceeds scientific disciplines and meets the need for new theories and conceptualizations. I have, to a large extent, allowed the empirical findings to guide me to remain open to new perceptions to understand inequality in NR. This theorizing, together with my reflexive approach, is used to create distance between me and the research object. In addition, theories also generate a conversational ‘partner’, allowing for the development of results that are relevant to multiple disciplines, approaches, and areas of interest (Alvesson & Kärreman, 2005).

3.1. ILLNESS INEQUALITY IN THE DANISH WELFARE STATE

The global interest in inequality has increased (e.g. The Atlantic Philanthropies, 2016; Savage, 2018, Personal Communication 8th August 2018) for various reasons. One of these is the fact that health and social problems are more prevalent in countries with income inequality (Marmot, 2005; Pickett & Wilkinson, 2010). From an international perspective, the Danish welfare state is considered successful (Therborn, 2012); it is one of the most comprehensive in the world and has an extensive redistribution of income together with a large tax-financed public sector that provides all its inhabitants free-of-charge health care services in the event of illness (Ministry of Health, 2016). It can therefore be questioned whether there is any point in studying inequality in such a universal welfare state. I argue (cf paper 3) that having this piece of the puzzle fall into place increases the likelihood that the same type of inequality will be identified in societies where inequality is overshadowed by discussions on e.g. economic factors (insurance, prestigious institutions and services, etc.). This makes it possible to direct the discussion on inequality to more hidden aspects that may previously have been overlooked. In addition, inequality in life and health expectancy is an increasing problem in Denmark (Brønnum-Hansen & Baadsgaard, 2012). My interest in this thesis concerns how social inequality relates to welfare and how institutional arrangements and public interventions associated with rehabilitation may impact the level and distribution of welfare when combined with social disparities between different social groups.

Both internationally (OECD, 2019; WHO, 2010; WHO, 2019) and at the national level (e.g. (Brønnum-Hansen, 2017; Danish Health Authority, 2011b; Ministry of

Health and Prevention, 2014), social inequalities in health are problematized, followed and documented. Such studies (e.g. Brønnum-Hansen, 2017; Diderichsen et al., 2011; Holstein et al., 2018) are predominantly epidemiological and based on statistical data showing correlations between socio-economic factors and various health behaviours, illness prevalence and mortality. While this research contributes with valuable knowledge to document social inequalities in health, a focus on individualistic behaviour and choices (agency) – which has been reinforced by the state's steering as part of New Public Management (Høgsgaard, 2018) – permeates the public health and epidemiology research results, placing the blame for not collaborating or taking enough responsibility on the shoulders of individuals. In addition, this research directs our attention to disadvantaged groups and their deficits, to be accounted for by politics. Such categorizing and defining masks the structural conditions that led to the inequality (Merrild & Andersen, 2019). Here, social science makes a valuable contribution by emphasizing the premises for and process of (dis)advantaging (Larsen 2016). Social inequalities can hereby be studied as contextual, social and dynamic processes taking place in both everyday life and institutional settings (structures) (Cockerham, 2005; Cockerham et al., 2017; Lehn-Christiansen et al., 2016) where fundamental class divides are addressed (especially discussed in paper 3).

3.2. THE CONCEPT OF FIELD - AN ANALYTICAL FRAMEWORK

Bourdieu's concept of field, as well as subsequent field analyses by other Bourdieu-inspired researchers such as Gorski (2013) and Carlhed (2007), constitutes the inspiration to consider the research object as situated in a broader historical, societal, political, institutional and ideological context (paper 1). These are elements that do not exist outside sociology but rather exist before and inside the research object (Bourdieu & Wacquant, 1992). All theoretical consulting requires modifications to fit the context of the contemporary Danish welfare state. Bourdieu's concepts were developed in Algeria and France in the 1950s, 1960s and 1970s (e.g. Bourdieu 1977; Bourdieu 1988; Prieur & Sestoft 2006); nevertheless, his theories focus universally on reproduction, and principles of power relations, when studying complex social transformations. This is because his broad theoretical project was developed with a high level of abstraction and flexibility and empirically tested both worldwide and in many contexts. In addition, Bourdieu encouraged the testing of applicable possibilities in other contexts (Bourdieu, 1998); taking his own advice, he applied and further developed on his theories in several fields, such as the cultural field of art (Bourdieu, 1996), the academic field (Bourdieu, 1988) and the economic field (Bourdieu, 2005). While Bourdieu has not conducted research on health, medicine or rehabilitation, recently, both Carlhed Ydhag (2020) and Pinell and Jacobs (2011) performed Bourdieuan-inspired analyses of the medical field. More specifically, historical and empirical studies have also been conducted on (re)habilitation (Feiring, 2013 & 2016; Guldager, 2018; Horne, 2016). Such studies constitute the foundation and inspiration for how to approach and demarcate the current study on NR as studied in paper 1. I am, however, cautious about defining NR as a (sub)field due to the notion by Wacquant and Akcaoglu (2017: 62) that *'...fields are relatively rare historical animals'*. In addition, this definition would represent a striving for positivistic premises, which this thesis attempts to break with (Møller, 2018). Instead, I consider the concept of field to be an analytical mindset, and adopt Bourdieu's advice to study it empirically. The advantage is that this concept can be used at different levels of aggregations (Bourdieu & Wacquant, 1992: 104) and can encompass various perspectives, including historical, social and political perspectives, thus enabling me to break with assumptions and practices that have been naturalized in NR. Autonomy is another crucial feature to explore in a field perspective (Defrance, 2013) since it can reveal NR's dependence on the surrounding world compared to its ability to maintain its own institutions (e.g. the rehabilitation hospital of Hammel Neurocenter) or determine its own agendas (e.g. consent to rehabilitation practices), among others. This theoretical framework enables me to distinguish between a field of consumption and a field of production. The field of production (as primarily studied in paper 1) possesses the power to define 'the truths' as well as the appreciation thereof (Harrits, 2017). In comparison, the field of consumption constitutes agents (in this study, patients and relatives) who do not contribute to the production. Analytically, such distinctions have been crucial to understanding the agendas and power relations framing the empirical findings (especially explicated in paper 3), such as the interview expressions and the observed practices of the participants (e.g. when discussing the further rehabilitation at the discharge meetings, where the professionals clearly possess the expertise and authority to assign the next step).

The Danish welfare state, I consider as a bureaucratic state constituting a meta power field regulating the fields at a distance through politics, legislation and by setting the value and exchange rate of the capitals (Bourdieu, 2010; Bourdieu 2004; Bourdieu, 2012; Hansen and Hammerslev, 2010). The state is a well-founded collective illusion exercising its power through symbolic efficacy. In NR this symbolic efficacy is e.g. reflected through the framing it imposes upon practices such as the unequal organisation and prioritising as explored in paper 3 and social categories and frameworks of perceptions as studied in paper 4.

3.3. SOCIAL CAPITAL AND SOCIAL NETWORK RELATIONS

Social capital has become widely considered one of the many social determinants of health (Abbott, 2009), which inspired me to use this concept as my initial entrance to the study of inequality in NR (paper 2). The Bourdieu-inspired perceptions (including the developing and refining of social capital by others, such as the American/Cuban sociologist Alejandro Portes (1998; 2000) provided me with the conceptual tools to study social capital and its direct exchange value in welfare state institutions. My interpretation of the concept of *social* capital concerns relatives' possessing, investing and transforming their capitals in the NR process, thereby generating 'goods' such as stays at attractive rehabilitation institutions, extensions to the standard period of economic compensation, and service aids. Social relations therefore only become capital when that capital is valued and convertible in NR. As an sABI renders the patient highly dependent on others, and taking the young age of the injured patients into consideration (where the social life aspect plays a crucial role e.g. in identity construction and social and geographical mobility), social capital is an interesting form of capital to explore. In addition, it is interesting to investigate since it is a capital form that can be converted to or used to gain access to other forms of capital, such as cultural or economic capital, adding nuance to the understanding of the complexity of inequality. With reference to Bourdieu (1986), I do not consider social capital an object but rather a feature in social relations; thus, social capital constitutes both an actual and a potential resource. Therefore, in my exploration of social capital, I have focused not on sociability but rather on the capitals to which social relations can be converted.

Bourdieu's and Portes' writings on social capital work as a starting point and are fruitful to catch underlying 'objective relations' structuring the social relations. This has enabled me to include a deeper layer than more substantialist thinkers that comprises actual, concrete relationships when considering social networks from an inequality perspective (Bottero, 2009; Bottero & Crossley, 2011). However, Bourdieu also has not explored conceptions and dynamics of social connections or the generative role of social interactions and bonds (Bottero, 2009; Bottero & Crossley, 2011). I have found that Bourdieu overlooks the possibility to explore and nuance how such capital unfolds in different life situations, among different people and social groups, and on a more concrete level. I realized that the concept of social capital is insufficient to explore the various aspects of social life which are also expected to relate to inequality.

Therefore, I searched for theoretical inspiration to elaborate on and operationalize the understanding of the social network relations of young adults and their families not only in a rehabilitation context but also from a larger social perspective of everyday life. The British sociologists Liz Spencer and Ray Pahl (2006) were consulted (paper 4), and their analytical concept of 'personal communities' was applied to approach and understand social relations in people's lives (in this case the families). Their theoretical framework was constructed within a British context and draws a universal picture (rather than studying the diversities of social positions), considering friendships at different life stages (including the young adult stage, with its characteristic social and geographic mobility and the contemporary emphasis on personal development and fulfilment) in the twenty-first century. An illness/rehabilitation trajectory constitute a life phase as well, but this has not specifically been explored by Pahl and Spencer. I employ their theories and concepts to challenge the traditional perceptions of who we consider relatives in an illness trajectory. To define dimensions and clarify the key terms of social relations, I found inspiration in Heaney and Israel (2008) and Valtorta et al. (2016). To operationalize the abovementioned theories and increase our understanding of the relationship between social capital, social networks and social support (SNSS), I turned to SNA (see section on methodology) (Boissevain, 1974; Lin, 1999) and hereby conceptualized a new theoretical framework to study inequality. The theory of SNA is inspired by the founders of sociology, such as Georg Simmel and his conceptualizing of new forms of social structure, relations and configuration in modern society, produced through the interweaving of social encounters (Andersen, 2007; Scott, 2000; Simmel, 1908). SNA provides an entrance to study family units and dynamics, transformation over time, and the explanations behind network processes in the families (paper 2 and 4).

The many different theoretical inspirations have sharpened my awareness and prevented me from equating social capital with measures of social networks and social support (SNSS) since complexity and ambivalence exist in social relationships and not all social ties and contacts are of similar value (Abbott, 2009).

3.4. PRISMS AND HABITUS

To move beyond the visible and spoken word, this thesis focuses on symbolic and ideological constructions in the social mind, drawing on Pahl and Spencer's (2010) concept of PRISM and Bourdieu's concept of habitus. Similarities exist between habitus and PRISM, as they both address the generative principles that structure actual behaviour (practices) and perceptions (Pahl & Spencer, 2010). These schemata reflect a person's class, ethnicity, regional background, etc. I use the concept of PRISMs (paper 4) to better understand how the social relations of the injured in a rehabilitation context are perceived by professionals, relatives and the young adult. Here, I also address how such perceptions can coalesce into clusters of roles with idealized and internalized models of behaviour (Pahl & Spencer, 2010) – in this case, as common perceptions and practices surrounding who is considered a relative. As part of this process, I lean on the assertion of Pahl and Spencer (2010) claiming that the personal community is not well established in the social mind, in contrast to the models of family, friends, and social network. In this regard, I argue that, to a large extent, the perceptions of professionals reflect the welfare state, and hence the institutional public work setting. However, differences between habitus and PRISMs are also evident. PRISM is a concept developed on beneficial friendships as explored when studying 'relatives' in paper 4, whereas habitus has a more general character influencing the ability to shape the rehabilitation trajectories as studied in paper 3. Another decisive difference is the aspects leading to reproduction; in line with Bourdieu, I emphasize dispositions as both shaped by past events and structures and shaping current practices. In addition, I acknowledge the layers of immanent and buried structures at various societal levels structuring the actions of the agents from the inside and conditioning our unconscious classification systems, as unfolded by Bourdieu (1984: 170). I find it necessary to include such layers and perspectives in a study aiming to understand inequality. Perspectives on the power differentials between friends and how power is gained and lost through friendship have not been explored by Spencer and Pahl (Elley, 2008). In addition, Spencer and Pahl can be criticized for reducing 'structures' to explanations on the ideals and norms of society reflected in the models of behaviour (Elley, 2008). Pahl and Spencer (2006) refer to Bourdieu in their work, and overall, there appears to be a level of compliance in these authors' underlying ontology which can be interpreted as a premise of how to perceive the world and develop their concepts. Ultimately, I find it fruitful and reasonable to combine the theories of Bourdieu and Pahl and Spencer, as they supplement each other; where some elements are elaborated in one of the theories, others are nuanced in the other. This combined approach allows me to explore how social relations are connected to inequality through reproduction in the trajectories of rehabilitation.

3.5. SOCIAL CLASS RELATIONS

In the 1990s, sociological voices argued for the 'death of class' (Atkinson, 2007). These claims have been refuted, with studies showing that class relations matter for the distribution of life chances and welfare state resources, as well as for health and illness (Aamann, 2017; Cockerham, 2005; Elo, 2009; Marmot, 2017). This is also the case in modern individualized societies (Savage, 2015), such as the Scandinavian countries, despite the absence of discussions of the existence of social class. In Denmark, which is a highly equalized society in many regards, class perceptions still influence attitudes and behaviour (Elo, 2009; Faber et al., 2012; Harrits, 2014; Prieur et al., 2008). This is despite class consciousness barely being used or acknowledged as an explanatory factor to understand inequality (Faber et al., 2012; Harrits & Pedersen, 2018).

The extensive economic redistribution by the Danish welfare state suggests that social class relations cannot be reduced solely to economic factors; therefore, I sought a broader operationalizing of social classes in contemporary Denmark. In paper 2 and 3, I found inspiration in the political debate book (Andersen et al., 2012) by The Economic Council of the Labour Movement (ECLM)[7], which includes socio-demographic (and self-reported) data on income, education, occupation and co-habitation in its social class categorizing. The authors categorize the Danes into five classes: 'upper class' (1% of the Danish population), 'upper-middle class' (9%), 'middle class' (24%), 'working class' (47%), and 'underclass' (20%). This book is based on data from Statistics Denmark and maps the development of Danish society from 1985 to the present. While such categorizing was used in paper 2, I subsequently realized it could be combined with the data (Harrits & Pedersen, 2018; Savage, 2013) from the focus group interviews, e.g. on (dis)taste, symbolic identity and belonging, and this realization enabled me to nuance the social class categorization (paper 3). This information provided me with knowledge on how the family constitutes a site for the accumulation and mobilization of capitals and 'classed practices' when encountering the rehabilitation institutions, as inspired by Bourdieu (1984; 1986). In addition, inspiration for paper 3 was found in Atkinson (2012; 2014) and his use of

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[7] ECLM is a Danish Economic policy institute and think tank working to promote social justice in Denmark.

family doxa to explain the natural and obvious navigating of some families during rehabilitation.

3.6. FILLING OUT THE RESEARCH GAP

In light of the identified literature and research gaps, this study contributes to the puzzle of how inequality is (re)produced in the Danish welfare state during a rehabilitation course by combining social class relations, framing field and state structures and the experiences of families and professionals to consider this phenomenon in its complexity. Social relations and social life aspects provide an entrance to empirical study this. In the following, I elaborate on the design and methodological approaches used to fill this gap.

CHAPTER 4. EMPIRICAL CONSTRUCTION OF THE OBJECT

The methodology section presents the project design, preparational work, and construction of the research object, consisting of a document review strategy, as well as observations, surveys and interviews, and finally the processing and analysis of the data material.

4.1. PREPARATIONAL WORK

As a newcomer to the world of NR, my preparational work was particularly important in order to understand what I would observe as well as what would be expressed in the interviews. While I do not claim to have gone 'native armed', as expressed by Wacquant (2014:48), I equipped myself with theoretical and methodological tools and at least some acquired knowledge on NR. This knowledge acquisition was an ongoing process, and one of the first attempts comprised dialogues with individuals with brain injuries and their families (contacts achieved through acquaintances and friends from my personal network) on their experiences with being a relative to or having acquired an ABI, the rehabilitation process and their 'new' life situation. I also participated in talks and seminars, e.g. arranged by Hammel Neurocenter, user organizations etc. The literature (fiction[8], non-fiction[9] and academic) also provided insightful knowledge, while writing paper 1 provided me with a historical, organizational and political overview of NR.

As part of my preparational work, I also sought experiences on a practical level and decided to draw inspiration from anthropologists doing field work. I therefore made an arrangement with a residential rehabilitation institution to follow a couple of professionals in their work with patients for almost a week. This was where I first met Harry and Wassin, two young adults whose everyday lives had abruptly changed due to illness and accidents. It was breath-taking and illuminating to me to realize how all-encompassing such a situation can be not only to the injured but also to their families, who were all strongly affected by the situation in various regards (emotionally, time-wise, logistically, energy-wise, economically) even though over a year had passed since the young adult's discharge. This experience was also able to answer some of my many questions, such as 'What does a life with an sABI consist of?', 'Who are the most present people in such a life?', 'What does their "new" life consist of?' and 'How does this presence affect their remaining life and relations (e.g. family dynamics)?' These preliminary questions were later refined, connected to the

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[8] An example of the fiction read is Jungersen (2012)

[9] An example of the non-fictive read is Fønsbo et al. (2018)

purpose of studying inequalities, and formulated into research questions 2, 3 and 4 in this thesis. In my search for answers, I talked to young adults, their families, and professionals and gained access to documentary sources (a diary containing small remarks on activities, moods, progress etc. made by professionals and parents as well as electronic records filled by the professionals) and conducted interviews with both professionals and relatives. As part of the pilot study, I also interviewed the young adults and tested various communication tools and strategies (see the section on 'interviewing the young adults'). Immediately after interviewing each young adult, I interviewed the professional who assisted me during the interview, asking them to nuance the answers of the young adult. At this time, the purpose of the study was not yet clear. I decided to omit these follow-up interviews from the professionals from the following studies for several reasons. First, I realized that the research paradigm I identified with does not strive for a larger truth to be revealed. Second, I considered it unethical to discuss these statements without the young adult being present. Third, it was unclear to me how to use this information, as it might comprise a mix of perspectives.

After the pilot study, I refined the data construction plans and clarified the research design as explained in the following section.

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4.2. MOVING FROM PILOT STUDY TO THE PHD DESIGN

After the pilot study, the project was supplied with additional funding and expanded to a PhD project. I also enrolled at the University of Aalborg and hence developed an increased sociological perspective on the research topic and a scientific approach initially grounded in the three R's: A rationalist epistemology, a relational ontology, and a reflexive methodology (Wacquant & Akçaoğlu, 2017). My altered approach entailed a distancing from considering the human being as a rational and a sovereign subject and instead led my attention to aspects that are neither conscious nor visible to the eyes of the researcher or the studied subjects. This entailed the need for a larger (re)constructive work to approach a phenomenon. The phenomenon in this study hereafter became inequality in rehabilitation trajectories, with a special focus on what I considered an overlooked perspective, namely that of the relatives.

As a result of my sharpened focus on inequalities, my empirical attention was drawn to the crucial cross-sectional and interdisciplinary discharge meetings,[10] which led me to include the participants earlier than I had in the two pilot studies. This also entailed practical advantages, such as easier access to the injured and their families as well as

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[10] The cross-sectional and interdisciplinary discharge meetings will hereafter be called 'discharge meetings'. Participators were various professionals from the rehabilitation hospital, municipality, relatives, in some cases the young adults if they were capable of participating, and the residential rehabilitation institution if decided at this time.

to the medical records. Including patients earlier in the process also facilitated heterogeneity among the trajectories because the ‘outcome’ was not yet known and it had not yet been decided where the young adult would continue their rehabilitation after discharge.

In order to study the changes and dynamics in social network relations, including in the two pilot studies, I supplemented these two cases with a longitudinal design by adopting an additional empirical construction 2½ years after discharge to align the time span (one year) between the empirical constructions of these trajectories and the other trajectories studied. Within this construction, a moving to new residential care settings was observed, but despite this, the life situation of both the family and the young adults had largely remained static. This might be partly explained by the limited functional improvements of the injured patients. However, this observation indicates a saturation in the data material for the remaining study with empirical constructions ½ year and 1½ year after discharge.

The two pilot studies were included in the overall analysis and argumentation as much as possible, thereby giving them a secondary status to support my findings. Meanwhile, these two pilot cases also provided me with valuable empirical in-depth knowledge due to their extraordinarily dense character (extra observations, formal and informal interviews, a detailed examination of the records etc.), directing my attention to aspects of social capital conversion and the social dynamics of social relations that required further elaboration and thus contributing to the larger empirical construct.

4.3. ETHNOGRAPHIC INSPIRATION AND A CASE STUDY DESIGN

The ethnographic tradition continued to inspire my exploration of the world of NR. My pedagogical and sociological foundation created a foreignness and a social distance from the world of NR and required a larger breadth in the data construction due to my reduced ability to anticipate what would actually be of significance to expound my research question (Prieur, 2002). A multiple case study design (Stake, 1995; Thomas, 2011) was here found suitable for an in-depth exploration of a contemporary and complex phenomenon (as shown in the section of ‘Illness inequality in the Danish Welfare State’) in its natural context because the phenomenon is too complex for one data source (Flick, 2018; Stake, 1995). However, not only various data sources but also different perspectives (the young adults, the relatives and the professionals) and over time (during HS-rehabilitation and until 1½ year after hospitalization) needed to converge through a methodological triangulation. Such an approach also aligns with a scientific standpoint of rejecting the belief that one person possesses a larger ‘truth’. Hereby, observations, documents, surveys and interviews all had a distinct value and together comprised a non-hierarchical whole. This approach enabled a productive collapse of the material necessary for the creation of possible new knowledge and new ways of thinking and the development of new explanations (Alvesson, 2003; Alvesson & Kärreman, 2005).

Overall, the construction of the empirical material has largely been characterized by a flexible approach (e.g. concerning communication strategies, time and places), accounting for the vulnerability and instability of this group of patients as well as divergent rehabilitation trajectories. In addition, considerations have been made to interfere as little as possible in the life of the families while also ensuring quality and stringency in the empirical material. In practice, my overall prioritization was to construct the data, whereas how and where this was done was less crucial (see the following sections for exemplification). This resulted in heterogenous data material, as some cases were closely followed to attain a deeper understanding and knowledge (extra interviews conducted and extra meetings observed), whereas in other, less-explored cases, less information was ultimately revealed.

4.4. DESIGNING THE OBJECT

A multitude of rehabilitation research studies focusing on a single point in time or a shorter time span to study a specific component of the rehabilitation process (Wade 2016) urged for a design in which I followed the families for a longer period. Through this longitudinal design, I was able to detect critical transitions in rehabilitation and the lives of the families (life transitions, status transitions, and the mundane transfers across institutions and sectors) (Harsløf et al., 2019; Højbjerg et al., 2019; National Board of Health, 2011; Slomic et al., 2017).

4.4.1. EMPIRICAL CONSTRUCTIONS AT VARIOUS TIMES

The first empirical (re)construction ‘before injury’ consisted of a retrospective construction of an individual’s social network.

The second empirical construction, ‘before discharge’, enabled me to capture the transition from one sector to the other, which is a crucial and challenging time for the families and entails a shift in the rehabilitation process. In addition, this transfer from the hospital to a home environment is crucial from a social perspective since the hospital in many regards can be characterized as living in an isolated social bubble, which is often not the case in a home environment with community (re)integration. Therefore, this empirical selection enabled me to visualize the social dynamics between contexts. The discharge meeting at the specialized rehabilitation hospital is characterized by an encounter between many different institutions at a time when crucial decisions concerning the future rehabilitation process are made; this highlights its importance in the study of inequality.

In the empirical construction ½ year after hospitalization, it was plausible to expect that a new kind of everyday life had emerged in the lives of the young adults as new professionals had developed relationships with them and their families, but the transfer from the hospital was still relatively recent, allowing them to recapture their experience of their hospital stay. In addition, I still expected them to be at the rehabilitation institution if this opportunity was provided after discharge.

The empirical construction 1½ years after discharge ensured a timespan of a year from the previous empirical construction. I expected this construction to entail changes in the institutional setting (indicating my striving to study complexity), as rehabilitation institutions are often granted by the municipality for a three- to six-month period. This empirical construction is also relevant when studying relatives since previous longitudinal studies indicate a change in the social and mental life situation of relatives for years after an ABI (Livingston et al., 2010; Schönberger et al., 2010; Witol et al., 1996). For example, Manskow et al. (2017) showed an increased caregiver burden and a lower level of life satisfaction for relatives 1 to 2 years after a sTBI.

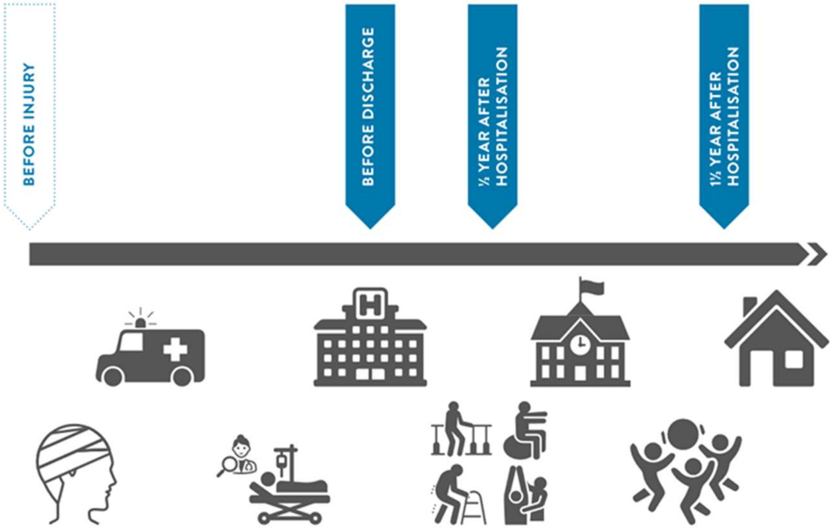

Figure 2: *Empirical points in time during the rehabilitation course*

4.5. Recruiting of young adults

My criteria for inclusion were young adults (aged 15-30 years old) with an sABI, no progressing diagnosis and families able to communicate in Danish without an interpreter in order to preserve as much objectivity as possible. To screen for severity of the ABI, the criteria for inclusion were highly specialized rehabilitation (HS rehabilitation) at a hospital, a hospital stay longer than 28 days (National Board of Health, 2011: 180), and expected needs of specialized and comprehensive rehabilitation and/or care needs after discharge as estimated by the HS rehabilitation team before discharge. This group constituted brain-injured patients who are often excluded from research due to their communicative and cognitive disabilities (Paterson & Scott-Findlay, 2002; Craven 2010).

In addition, I strived for a broad representation of young adults in terms of sex, age (as the age of 18 constituted a juridical border), ethnicity, functionality based on FIM[11] scores at time of discharge, to some extent socio-economic position, and admission to various organizational and institutional framings (region, municipality and rehabilitation institutions) and services after discharge. Not all these characteristics have been given the same level of analytical attention in the research; some of them have constituted the centre of the analysis, while others have been used to contextualize or discuss the results.

The two pilot study cases were included in the summer of 2015 while the young adults were at the residential rehabilitation institution. The remaining eight young adults were included in the study in the period from December 2015 until March 2016, when they were at the specialized rehabilitation hospital.

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[11] Functional Independence Measure assesses motor and cognitive skills as well as dependence on help and care. The FIM scale ranges from 18 to 126, where 18 indicates the lowest level of skills and the highest need for help and care.

Sociodemographic characteristics		**n = 10**
Sex	Female Male	4 6
Age at discharge	Younger than 18 Older than 18	3 7
Social class	Middle class Working class Under class	2 5 3
Functionality		
Severity of brain injury (FIM score)	18-49 50-99 100-126	5 3 2
Organizational framing		
Region (access to HS Rehabilitation)	Same region as HS Rehabilitation Other region than HS Rehabilitation	6 4
Municipality	Number of different municipalities	6
Setting/context after discharge[12]	Rehabilitation institution Care home Home	6 1 3
Service provision after discharge[13]	Municipal institution Institution purchased by the municipality	6 4

Table 2: *Sociodemographic profile, functionality and organizational framing of the included participants*

An additional four young adults were interviewed for a separate purpose (an evaluation of the youth mentor service (Bystrup, 2017)), but were also included for

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[12] The service provision after discharge is provided by the home municipality of the young adult at a municipal institution, at purchased providers or at home.

[13] (same as footnote above)

perspectivation in paper 2 to extend the heterogeneity among the representation of the young adults (e.g. by also including representation of the upper-middle class) and obtain results across a wider range of cases.

During the process of inclusion, it became evident that I was a newcomer to a field in which only the ‘consecrated’ had direct access to patients. I had to adapt to this subordinate position, complying with the set rules. This entailed a professional assisting me in identifying newly hospitalized patients within the inclusion criteria and another professional initiating the contact between me and the families. However, this gatekeeping of (‘the consecrated’) professionals also provided the privilege of me being able to draw on the confidence often built between the family and professionals from the department team. I expect that this positively affected the families’ willingness to be included and increased the ethical responsibility for me as the researcher to assure them of their voluntary participation and possibilities of withdrawal (see the chapter on ethical concerns). I experienced that some professionals took on a gatekeeping role, attempting to protect the families from the expected distress of participation. This might have hindered inclusion (Ries et al., 2020) since the professionals created their own ‘criteria’ of exclusion to the project, estimating, for example, whether some families were too vulnerable or burdened. This also highlighted the predominant perceptions in the field of patients and their families as people to be protected who were not in charge of making decisions for themselves. I responded by insisting on giving all families the possibility to decide themselves whether they wanted to participate, as a fundamental component of this study was breaking with existing hierarchies, striving to achieve broad heterogeneity among the included participants (including heterogeneity in vulnerability levels) as well as for ethical reasons. Three families rejected the invitation of inclusion with the arguments of feeling too overloaded, having limited energy and already being forced to navigate too many people and services.

4.6. EMPIRICAL DATA SOURCES

The multiple case study design resulted in the following sources:

- Political and historical documents on NR
- Professional records from both hospital and rehabilitation institutions
- Observations of hospital discharge meetings, the everyday life and context of the young adults and the family environment
- Interviews with the young adults
- Focus-group interviews with the families and the professional(s) of the injured
- Survey answered by the young adults, family members and professionals

These sources are presented in the following table.

	Young adults		**Family**		**Professionals**	
Time after hospitalization	6 months	18 months	6 months	18 months	Before discharge	6 months
Data sources	Surveys Interviews Observation (activities)	Surveys Interviews	Surveys Focus group interviews	Surveys Focus group interviews	Records Observation (discharge meeting)	Records Surveys Focus group interviews
Professional Records					10	8
Observations	7	2	8	9	5	
Surveys	6	8	24	27		20
Interviews	6	8	8	9		12

Table 3: *Overview of empirical data construction*

My ethnographically inspired research approach also led me to experiment with and register additional data materials. Examples of such additional data sources include the following:

- Phone calls from the families, often when they were in a desperate situation, feeling helpless and reaching out to anyone who was around them.
- Photographs taken in the institutional apartments of the young adults to show the materializing and ambivalence of their life situation (e.g. witnessing disability using large assistive technologies) and a large notice board bearing the individual's aims and progress combined with a 'normal' interior (chairs, dining table, couch) and pictures of previous life achievements.
- A registration of cancellations or occasions of interview appointments that had been forgotten by both the institutions and the families.

- Informal talks with professionals, relatives and young adults when contacted concerning inclusion or arrangement of interviews etc. or during coincidental meetings at the hospital.

4.6.1. WRITTEN SOURCES

The written sources for this study consisted of political and historical documents related to our field-inspired analysis of NR (paper 1) as well as the medical records of the young injured individuals (paper 2, 3, 4). The advantage of using documents as a data source is that it is not researcher-led or researcher-promoted but rather a naturally occurring activity and piece of data material (Rapley, 2018). Therefore, such data is disconnected from self-presentation, enabling researchers to access how various politicians and professions routinely think and act (Jacobsen & Duedahl, 2010). In addition, documents provide access to perceptions on practices which can reveal social objects that are invisible to the professionals themselves and can only be (meaning) generated via theoretical objects such as 'doxa'.

4.6.1.1 Political and historical documents – a document review strategy

Bourdieu's field theory as well as the concretization thereof offered by the Bourdieuan researchers Kropp (2009), Delica and Mathiesen (2007) and Esmark (2009) inspired me to create a systematic registration of political and historical documents (see appendix 1 in paper 1) as a concrete tool to map the sources of material relevant for further historical analysis. As described in paper 1, the central historical agents and events were initially identified through a document review strategy of the 'anthropological composition' of NR (Løvschal Nielsen, 2004) within various agencies, including hospitals, rehabilitation institutions, and user organizations, in combination with the sociological work of Delica (2007) on administrative and organizational changes for professionals working with persons with brain injuries. Such a strategy was useful to gain an overview and circumvent the difficult and wide-ranging work of excavating all of these documents, allowing me to instead prioritize the mapping of more contemporary political documents to identify the leading positions in NR. This was continued by a second review process to identify relevant current political documents (legislation, announcements, guidelines, reports) and authorities and create an overview of changes in the dominating political actors throughout the years. The process was based on the reference list of the two most recent disease management programs published by the dominating political authorities in NR (the Danish Health Authority and Danish National Board of Social Services) as well as an audit from the National Audit Office of Denmark (NAOD). I further classified and selected the documents identified through the first and second review processes according to the following criteria: (1) documents representing the public sector for the whole country concerning ABI service provision for adults; (2) documents issued by political and professional authorities; (3) documents related to the rehabilitation of ABI; and (4) documents concerning adults. General legislative documents (for example, changes in health legislation) were excluded in order to focus the analysis specifically on NR, but with the knowledge that this is an artificial demarcation since NR is also influenced by the surrounding fields. In total 31 political documents were located (marked with (*) in the list of references of the paper). The systematic approach involved the registration of documents regarding year, author, type of document, objective/purpose, target group, and content/emphasis to create an overview. Three key documents authored by the dominating political authorities were selected for further detailed analysis, as they represented different approaches, were the most contemporary (in order to draw a present picture) and comprehensive (to create a broad and overall view of NR) and included published regulations with a significant influence on NR. The documents are the National Board of Health (2011), Danish Health Authority (2011) and Danish National Board of Social Services (2016).

4.6.1.2 Professional[14] records[15]

Professional records were collected from the specialized rehabilitation hospital (all 10 young adults) and from the residential institution if the participant had attended one after hospitalization (8 young adults). I consider both the acquisition and the content of the professional records to be part of my ethnographic field work, reflecting how they form part of practice (how they are read, discussed, referred to and used). Hereby, I consider these records as an approach to draw closer to NR and its practices, traditions, hierarchy, authorities, struggles etc. (Asdal & Reinertsen, 2021). This ethnographic work included gaining access to the records which were only accessible to the ‘consecrated’ professionals at the hospital. Therefore, a secretary functioned as a gatekeeper, whom I asked to withdraw the necessary information (primarily on relatives, the municipality and other collaborating partners). The procedures for the residential institutions varied due to the local politics of the institutions; in some cases, I was allowed access to their documentary system and could peruse the many hundreds of professional registrations myself, while in others, a professional extracted the information from the registration system based on categories I had set. This variation reflects the range of rehabilitation practices where information was either closely guarded and I was only handed a few pages, thereby reducing my possibilities of insight or, on the contrary professionals showed me unlimited confidence by providing me with a password and gave me unrestricted access to the system. These

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[14] The term ‘professional’ covers a wide variety of welfare state professions (medical doctors, therapists (occupational, physio and speech- and language), neuropsychologists, neuro-pedagogues, pedagogues, nurses, social and health care assistants and social workers) with synonyms found in literature such as practitioners, providers and (professional) caregivers. The professionals represent the following institutions: The specialized rehabilitation hospital, residential rehabilitation institutions, care homes or municipals.

[15] The term ‘professional records’ includes both the medical records from the hospital setting and the records from the rehabilitation institutions.

different gate-keeping practices resulted in a heterogeneous data set ranging from several hundred pages to a few pages of censured records.

The records were an 'easy' accessible source of information to capture the voices of the represented institutions. Such information was considered challenging to obtain from other empirical sources, such as observations (biased because of my presence, time-consuming for me as the researcher) or interviews (time-consuming for the professionals, implying challenges with interviewees' ability to recall and describe concrete episodes or maintain perceptions of concrete relatives (as studied in paper 4) and only including perceptions and perspectives represented by the few interviewees). Unlike these other sources, the records encompassed the voices of various professionals. Support for considering them as an orchestrated voice contains the educational socialization in the welfare state profession of all the professionals writing the records, the ICF principles for rehabilitation, and their embedded position in a certain culture of the institution. Hereby, these records reflect the institutional doxa. The unification of these voices thus neglects the nuances of the professionals, each of whom represents different professional practices, traditions, and positions in the hierarchy as well as inhabiting their own unique habitus and social position.

The inspiration to analytically approach the professional records was found in the document review strategy (Esmark, 2009; Kropp, 2009) which was used to create a chronology of collaborating encounters and 'events[16]' with a focus on specific agendas, power relations and institutional changes. This was achieved through the registration of the same kind of information for each encounter and 'event': Date, institution, purpose, agents (e.g. municipal, relatives), presence form (e.g. physical meeting, physical interaction, phone, mailing/SMS) and content/character. These registrations were, in most cases, further nuanced in subcategories; for example, relatives were further divided into parents, siblings, friends etc. The professional records were included in paper 2, 3 and 4.

4.6.2. OBSERVATIONS

This observational approach was an implicit part of this study in all kinds of encounters with the families and observing the young adult in an everyday activity (e.g. a session with a speech therapist, a group session with a physiotherapist, an eating situation with others at the institution) was perpetuated in the form of spontaneous written notes and reflections. However, more systematized observation (following an observation guide (see appendix C) in order to guide my attention) were made at the cross-sectorial and interdisciplinary hospital discharge meetings and with the young adult in an everyday activity (e.g. a session with a speech therapist, a group session

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[16] Events is a term used for e.g. an operation, a meeting or the accident that caused the brain injury.

with a physiotherapist, an eating situation with others at the institution). I consider observation a powerful methodological tool to understand social practices guided by a practical sense and non-verbalized logic since agents are not transparent to themselves (Bourdieu, 2003; Prieur & Sestoft, 2006). First-hand observation constitutes a methodological entrance when aiming to explore and understand unequal macrostructures in NR expressed in the observed micro-processes (e.g. transformed in practices and sayings) (paper 2 and 3).

My observational role was characterized by passive participation (Spradley, 1980: 59) at both the discharge meetings and when observing the young adults, as this was considered the least interfering and most demystified way of observing. I placed myself at the periphery of a large table together with the other participants where they could see me but I did not take a central seat. I presented myself and explained my presence, knowing that this explanation was important to how the families and professionals positioned me (see the section on ‘framing the researcher and the research project) (Hansen & Tjørnhøj-Thomsen, 2020; Larsen, 2009). At the discharge meetings and when interviewing, I asked for the participants’ acceptance to be recorded.

These observations also included the writing of field notes where Emerson et al. (2011) was consulted. I did not take field notes while attending the meetings, activities etc. since retrieving a notebook would most likely have caused more attention than was desired, disturbing the practices and possibly generating discomfort among the observed; also, it would have removed some of my presence/attention from the room. Instead, I tried to remember the situation and jotted down my observations in cues as soon as I returned to my office or car. The same day, when returning home or to my office, I expanded these jotted notes into a coherent text in order to remember as much as possible. In this coherent text, I first wrote for myself but afterwards rewrote the text with added details, considering my co-authors/supervisors as a future audience. This text included a mix of concrete descriptions of episodes, appearances of the participants and their surroundings, preliminary interpretations, moods and reflections on my own appearance. A look back at my field notes show an ongoing development reflecting my increased experience with writing jotted notes and converting these to text; the notes became more focused as I continued to clarify my research questions and increased my familiarity with NR. The latter change in my perspective may have also introduced the disadvantages of my questioning fewer practices and taking more for granted. In addition, my acknowledgement of this data source continuously increased as I realized how much knowledge was stored in my field notes. These observational texts enabled me to recall atmospheres, dynamics and immediate perceptions rapidly, even a long time after the observation had been made.

	Discharge meeting	**Young adult**	**Interviewing relatives**
Number	5 (out of 6 held)	9	8[17] + 9[18] = 17
Length	40-75 min	30-70 min	70-170 min
Persons included in the observation	• Professionals from HS rehabilitation • Municipality • Relatives • (Young adult) • (Future rehabilitation institution)	• Young adult • Professionals • (Relatives) • (Peers)	• Relatives
Focus for the observation	• Dynamics and power relations between the participants/social positions • Struggles (issues of discussions) • Capital conversion • Doxas (naturalized perception of reality)	• Life content and focus areas • Relation to professionals/relatives/other disabled individuals • Capital conversion Rehabilitative surroundings • Communication abilities and strategies • Confidence-building between me and young adult.	• Family relations, roles and dynamics • Materializing of social position including family members' life situation (body signs and surroundings)

Table 4: *Overview of primary observations*

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[17] Eight families were observed in relation to the interview ½ year after discharge.

[18] Nine families were observed in relation to the interview 1½ years after discharge.

4.6.3. SOCIOLOGICAL RESEARCH INTERVIEWS

Mastering an interview situation is a habitual practice whereby I drew on experiences from being an apprentice (Bourdieu, 1999; Callewaert, 1998) while working with Kristian Larsen when studying marginalized people on Langeland (Dahl & Larsen, 2009)[19]. Such mastering also requires a reflex reflexivity (Bourdieu, 1999) both as the interview is conducted and in post-reflections after the interview. In practice, such reflections contained the administration of my role as a researcher including the formulation of questions, my ability to release their stories, and my automatic interpretations, power asymmetry etc., which were written down immediately after the interview. On a longer time frame, I continuously used collegial units[20] to discuss these aspects and be confronted with other possible interpretations and reflections. Through this, and together with familiarizing myself with the interview guide, I gained experience and improved my mastering of the interview situation throughout the project.

My mental preparation before the interview included reading the transcripts from the discharge meeting and consulting relevant medical journals. Before I conducted interviews for the second time (1½ years after discharge), a thorough reading of the interview transcripts from the previous interview (conducted ½ year after discharge) provided the basis for reflections and served as preparation for what to follow up on or have expanded. Furthermore, before, during and after the interview I used genetic and generic comprehensions to construct the families' social position in the social space. This comprehension was gathered from observations (e.g. how they performed, their clothing and attitude) at the discharge meeting and their homes (location, interior, books on the shelves etc.) and their responses to the surveys (e.g. concerning education, job, social relations)). This process helped me to understand the social conditions of which the families were inevitably the product and to explain their practices and expressions related to the rehabilitation process as necessary (Bourdieu & Wacquant, 1992: 7). Hereby, I conducted a mental exercise (Bourdieu, 1999: 22) by entering into the families' distinctive personal history and uncovering the immanent social structures. This uncovering was facilitated by interviewing the young adults in their everyday setting, the parents in their homes and the professionals at the rehabilitation institution/municipal buildings in order to frame their expressions and gain knowledge of the social and objective structures and tensions.

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[19] My maiden name was Dahl.

[20] An example is the PhD course 'Empirical workshop – a course in qualitative method' and the monthly 'enhedsmøder'

A semi-structured interview guide with themes and open-ended questions was developed for each of the interviews (one for the young adults[21], one for the families and one for the professionals) (see appendix D; these guides served as a tool for me to act as a 'midwife' during the interviews in order for the participants to reveal their unique stories (Bourdieu, 1999). In practice, this entailed asking for further explanation, repeating what participants were saying, and clarifying their arguments, all reinforced by inviting body language. Hereby, I was largely left to rely on my intuition and habitus instead of a structure planned beforehand (Bourdieu, 1999: 612-614). Through this framework, interviewees shared their experiences of the rehabilitation process, the challenges (struggles) they had faced, and how they had approached these challenges (strategies, capital conversion), laying the groundwork for me to prompt narratives (Czarniawska, 2004). The interview guides were combined with questions following up on the last interview ½ year after discharge or knowledge gained from the records. The disadvantage of this interview approach with limited steering was the production of a very large, detailed and heterogenous data set.

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[21] The interview guide for young adults with good cognition has been attached but modified for each of the interview with consideration of their level of cognition, possibilities of expression and their individual situation.

	Young adults		**Family**		**Professionals**[22]
Time after hospitalization	6 months	18 months	6 months	18 months	6 months
People interviewed	Young adult	Young adult	Parents Siblings (Friends)	Parents Siblings Girl/Boyfriend	Professionals from institution or municipalities
Interviews	6	8	9	10	12
Number	6	8	25	28	20
Length	30-70 min		60-160 min		30-90 min
Focus/purpose of the interviews	• Experiences with the rehabilitation process • Challenges (struggles) met • Approaching of challenges • Capital conversion • Social relations • Everyday life and well-being		• Experiences with the rehabilitation process • Challenges (struggles) met • Approaching of challenges • Capital conversion • Strategies • Social relations • Family dynamics • Handling of their new life situation		Collaboration partners Rehabilitation approaches

Table 5: *Overview of interviews*

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[22] Professionals consist of therapists (occupational-, physio- and speech and language therapists), pedagogues, social and health care assistants and social workers

4.6.3.1 Interviewing the young adults

Involving people with ABI in research entails unresolved legal and ethical issues and the need for carefully explained research solutions (Pape et al., 2004). Flexible and creative strategies were used for each interview to overcome as many challenges and barriers as possible. Overall, the young adults interviewed had varying degrees of cognitive and physiological impairments affecting their ability to recall and articulate their experiences and perceptions. This was considered and addressed through concrete tools and strategies acquired from consulting the speech and language therapists at Hammel Neurocenter combined with inspiration from the research literature (e.g. Paterson & Scott-Findlay, 2002). Examples of these strategies include visualizations (e.g. young adults rating their answers on a smiley scale, inspired by Murphy et al. (2013); illustrative items from the COAST scale (Long et al., 2008); a visual version of the CARE measure (Murphy et al., 2013); and a talking mat consisting of picture symbols/pictographs detailing the topics and supporting the answers (Murphy et al., 2005)). In two of the cases, a professional who knew the injured young adult assisted me with their communication strategies and 'translations' of the young adults' limited options for expression (movement with a finger, blinking with the eye etc.) (Kagan, 1998). Two other individuals had too limited interactional abilities to participate. The young adults were interviewed separately from the rest of the family to leave room for both sides to speak freely without needing to consider each other's feelings and opinions as well as to provide time and space for the young adults to express themselves. This data was included in paper 3 and 4.

4.6.3.2 Focus group interviews

The establishment of the focus group interviews with the families involved a balancing of ethical considerations and what was practically possible. In an ideal world, I would have preferred to ask the young adults to point out their 'relatives' before bringing them together for the focus group interview. However, due to reduced cognitive and communicative functionality of the young adults, their young age and their increased dependence on the mother/parents due to their illness, this was not always possible, at least not through the most straightforward method. I started by asking the young adults who they would point to as relatives in the six cases where they were able to express this in some form. Hereafter, I involved the closest relative as appointed by the professional and asked which additional relatives they would identify for participation. My starting point was asking for the inclusion of both parents (even when divorced), siblings, and boy/girlfriends of the young adults as participants. However, to avoid reinforcing conflicts within families, no larger attempts were made to insist on including oppositional individuals (e.g. when the closest relatives consisted of conflicting parties). In one case, the initial dialogue with the mother also led to an additional focus group interview with 16 friends because of their significant involvement. Such an inclusion approach addresses gaps and silences in the young adult's social network and reproduces common perceptions (of the nearest relative and the professional) regarding who should be considered a relative.

These focus-group interview with the families were included as data in paper 2, 3 and 4).

A focus group interview was also conducted with the respective professional(s) of the injured young adults (therapists, pedagogues, social and health care assistants and social workers) (included in paper 3 and 4). The number and positions of the professionals interviewed were determined by those who responded to my invitation soliciting interviews with the professionals who worked most closely with the young adult. The duration of the interview was defined by the available time of the professionals. This was in some cases defined by professionals based on whether colleagues could adopt the care of the patients during the interview, but in other cases, it was influenced by management-level prioritizations or collaboration agreements with Hammel Neurocenter. Overall, it became clear to me that the time and ‘working hands’ of the professionals comprised a limited resource at the rehabilitation institutions.

Watching the interplay between the participants as part of the focus group interviews was a way to acquire observational knowledge of family dynamics and team collaboration (Barbour & Barbour, 2018; Halkier, 2016). In addition, I gained insight into participants’ negotiation of meaning formation (e.g. perceptions of the rehabilitation process, perceptions of and relations with relatives/professionals). However, there are also disadvantages associated with focus group interviews, such as the participants’ stories being adapted not only to the interview situation but also to each other, compounding the difficulties in creating space for the views of each participant. I therefore directed questions to individual participants during the interview if I noticed that I had not heard their voice (Halkier, 2016).

4.6.4. SURVEYS AND SOCIAL NETWORK MAPPING

Three different surveys with different purposes and various lengths were constructed for the young adult, the relatives and the professionals, respectively (see appendix E)[23].

In practice, the surveys for the family members were sent by mail and they were asked to complete and return these prior to the interviews. However, after several unsuccessful attempts, I asked participants in-person to fill out the questions before or after the interview. When the participants were unable to complete the survey (e.g. difficulties with reading/writing the answers), I noted their answers. This approach secured a high response rate but also introduced biases, as discussed in the ‘challenges of constructing the network maps’ section. The surveys of the young adults were completed by the young adults themselves if they were capable of doing so; in cases

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[23] At this time, the project had the title: “Et stop på vejen?”

where young adults were incapable of completing the surveys themselves, I asked them the questions and completed the surveys based on their answers.

	Young adults		**Family members**		**Professionals**
Time after hospital	6 months	18 months	6 months	18 months	6 months
Surveys	6	8	24	27	20
Focus/purpose of the surveys	Construction of their social network map		Construction of their social class relations and capital possession Construction of their social network map		Construction of their professional standpoint

Table 6: *Overview of the surveys*

The survey of the professionals contained questions on age, education, job position and work experience to enable me to position them as a voice of the welfare state institutions (see the argumentation in the section on ‘professional records’). Since the professionals’ expressions were not considered a primary perspective but rather a representation of an institution, to prioritize the professionals’ limited availability and attempt to prevent an overload of data, these surveys or interviews did not include questions that enabled me to construct their individual social positioning; rather, they focused on allowing me to construct an orchestrated voice (paper 4).

The survey of the relatives contained questions contributing to the construction of their social class relations and capital possession (questions on cohabitation, education, job situation, income and knowledge acquisition concerning the rehabilitation). This survey was inspired by the National Institute of Public Health (2013) regarding socio-economic demography in a Danish social and health care context. These questions were omitted for the young adult survey due to considerations of fatigue and other aspects of the brain injury impacting the young adults’ ability to participate in the study (Pape et al., 2004) and hence respond to the surveys. Instead, a family position was constructed (cf. Atkinson 2012; 2014) that considered the family as an entity for class and capital possession (included in paper 2 and 4).

The surveys for both the young adults and the relatives included a name-generator list[24] to explore various aspects of the participants' social life relations, such as nature, strength and dynamics. To complete this list, they were asked to name people who were significant to them (before the injury, ½ year and 1½ years after discharge) and state the nature of the relation (e.g. family, neighbour, professional) and the frequency of the contact. Inspiration for this list was found in the Social Network Analysis (SNA) literature, such as Fischer (1982), Wellman (1982), Scott (2000), Borgatti et al. (2013), Bidart and Charbonneau (2011), Granovetter (1983), and Montgomery (1994) as well as in the more qualitative approaches (QSNA[25]) described by Alexander (2009), Trotter (1999) and Heath et al. (2009). These structural aspects of the social network relations were combined with functional aspects (provided through the observations, focus group interviews and medical records), including trust, reciprocity, conflict and hierarchy, to explore participants' social relations and capital (Abbott, 2009; Wittel, 2001) (included in paper 2 and 4). ¨

4.6.4.1 Visualization of the network maps

Converting the name-generator lists to qualitative mapping can produce many different spatial visualizations due to the manual approach (in contrast to the majority of social network mapping, which is conducted by statistical programmes on larger populations). The visualization style created in this thesis contains the injured young adults and/or their family relations constituting the ego(s) (a square-like figure), and the relations they mention being linked to constituting alters (placed in circles). The *nature* of the relations is indicated by different colours (family being red, friends being orange, co-workers being turquoise, girl/boyfriends being purple etc.) (Heath et al., 2009). *Reciprocity*, representing a basic principle in most perspectives of friendship but challenged when a life crisis such as illness occurs (Spencer & Pahl, 2006), was marked as a double arrow. In addition, the *quality* of a contact, based on the frequency of the contact between the ego and alter (Granovetter, 1983; LeCompte et al., 1999; Wellman et al., 1988), was visualized by the thickness of the arrow. Green contours indicate individuals who constitute the family core, as estimated based on the survey responses as well as the (focus group) interviews. Red contours indicate individuals (besides the young adult) who is mentioned as relatives in the medical records at the HS rehabilitation hospital.

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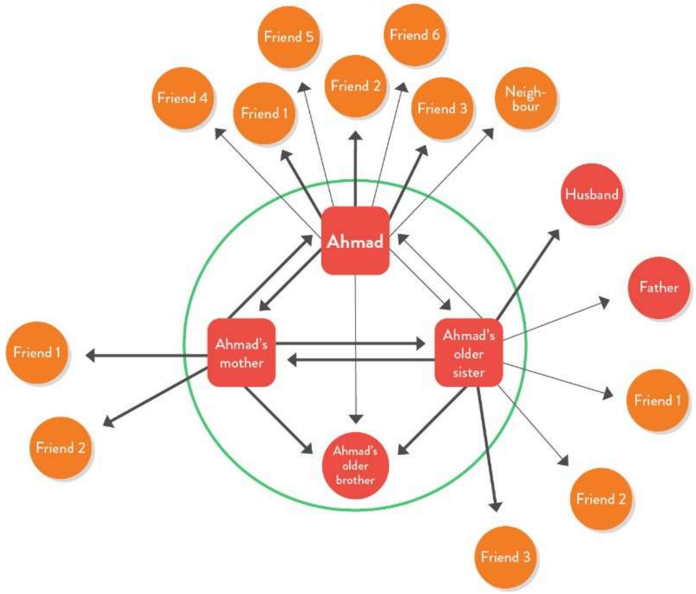
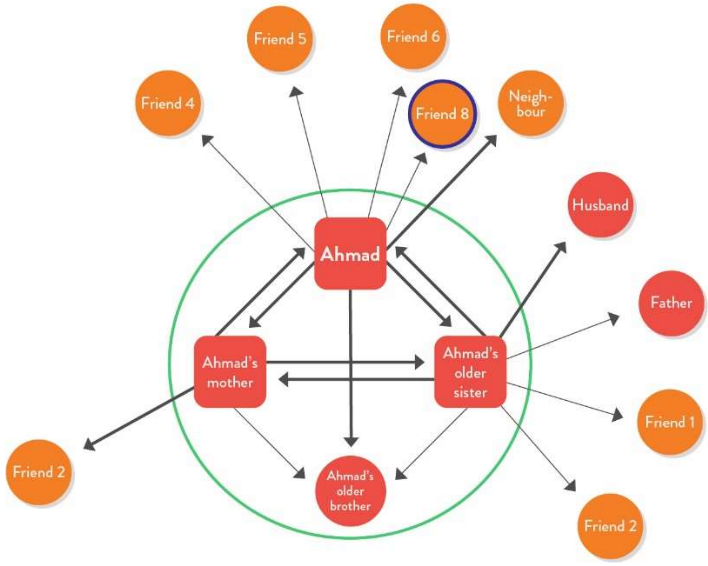
[24] Social class designations are based on self-reported information on income, education, occupation and co-habitation (cf. Andersen et al.2012) categorizing Danes into five social classes: 'Upper class' (1%), 'upper-middle class' (9%), 'middle class' (24%), 'working class' (47%), and 'underclass' (20%).

[25] QSNA is a term borrowed from Heath et al. (2009) and is an abbreviation for Qualitative Social Network Analysis.

The dynamics of the networks are visualized by repeating these network constructions ½ year and 1½ years after discharge together with the retrospective drawing of a participant's personal community before the injury. An example of these network maps is shown below as well as in paper 2 (including before the injury and ½ year after hospitalization) and in paper 4 (including only the personal community of the young adults before the injury, ½ year after hospitalization and 1½ year after hospitalization). Unfortunately, due to time restrictions networks such as the ones below that contains all three empirical points in time for the whole family has not been included in any of the articles despite the empirical material being available. Instead, reflections on how such data could be approached in future studies have been included in the perspectivation of this thesis.



“AHMAD”
BEFORE INJURY



“AHMAD”
½ YEAR AFTER HOSPITAL

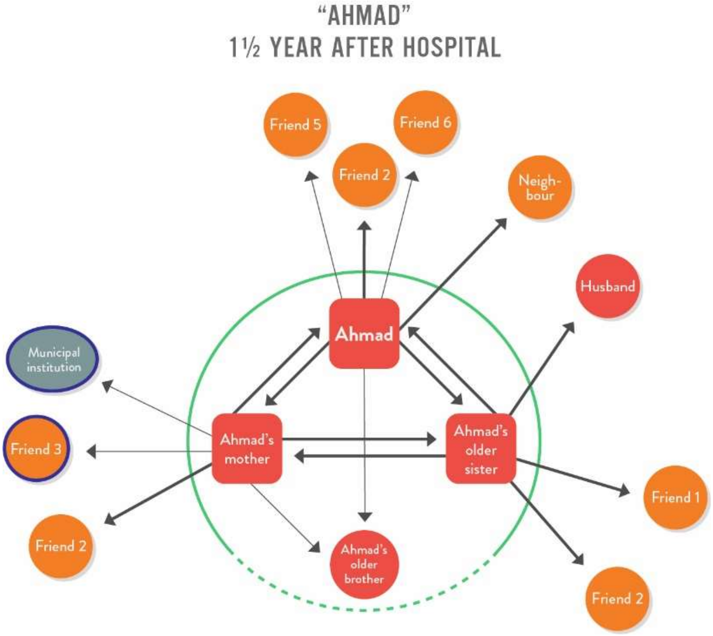


Figure 3: *Example of social network maps of the family of Ahmad before injury, ½ year after hospitalization and 1½ year after hospitalization*

4.6.4.2 Challenges of constructing the network maps

Methodological challenges, errors and bias are linked to the construction of network maps and might challenge their internal validity, as e.g. addressed by Almquist (2012). Such bias includes an inconsistency in perceptions of what it means 'to be close to' and 'to be in touch with', which might result in variations in answers (Abbott, 2009). Another bias is the recalling ability of participants, whereby Almquist (2012) found errors rates of up to 20% in recalling friendship egonets, and even 3% in relation to best friends, due to memory loss, even in participants without disabilities. In this case, the recall of a young adult's network before an injury is a particular challenge since memories decay over time (Bell et al., 2007). For individuals with brain injuries, fatigue, memory loss and cognitive challenges expectedly might be exacerbated by an ABI, reducing recall ability. However, relatives also expressed memory loss and fatigue as reactions to their challenging life situation. In hindsight, it is therefore easy to assess the surveys as being too long and with overly abstract and unclear formulations. During the data collection, the attempt was made to reduce the expected bias in self-reporting through methodological choices, such as formulating the questions in the name generator as seeking relations with emotional closeness; asking for the name of their alters (in contrast to anonymous alters such as simply 'friends'); delimiting their answers to the closest relations (in comparison to e.g. all relations since forgetting increases as network size increases); and being the only interviewer (to avoid effects of interviewer differences) (Bell et al., 2007; Marsden, 2003). Although I was the only one formulating the questions, smaller differences in the formulation appeared; however, according to Straits (2000), these variations have little or no effect on reported egocentric networks. The name generation entails a self-presentation; having many 'friends' might be a criterion for success that some might strive for, and these participants may therefore report more relations than others who do not share this perception. That said, this effect was determined to be less relevant for the interpretation of this material, as the name generation in this study is primarily comparing the same person's communities at various points in the trajectory (comparing data from ½ year to 1½ years after discharge) rather than comparing the communities of different people.

In addition, the construction of social network maps also constituted a filtering process with the injured participants and/or their mother/parents nominated for inclusion (see the section on 'inclusion to the research project'). This process expectedly entails gaps and silences in the constructed networks and an awareness of a participant's constructed map as only a subset of the broader network; no claim is made of having constructed *the* network. Such gaps and silences became visible during the interviews when relations who were not listed in the survey were mentioned. In order to overcome some of these biases and limitations, the survey results were supplemented by combining these network maps with other data sources (records, interviews and observations) for elaboration, contextualization and verification.

4.7. SOCIAL POSITIONING STEERING MY OUTLOOK

My social position as a researcher, a professional with a pedagogical background and a mother steered my outlook and predisposed me to feel, think, and behave in certain ways; the effects of my position is further elaborated in the section 'framing the researcher and the research project' (Emerson, 2011; Bourdieu 2003). These effects included (unconscious) bias and stereotypes; however, I used the approaches of awareness and continuous reflections to handle these factors and maintain as much objectivity as possible (Bourdieu, 1999), and reduce their influence on my encounter with the families (Harrits, 2020).

Since I constructed all the data material myself, significant reflexive work had to be done to understand respondents with whom I shared less social proximity and fewer commonalities in values and life perspectives. However, my social position was also advantageous in allowing me to draw closer to some participants, a process mitigated by the constant balancing act of not projecting myself onto them and their expressions. I was privileged by my profession as a public-school teacher to become used to working with people from many different life conditions, automatically reducing stereotypical reactions (Harrits, 2020). I met all the participants with an open mind and respect accepting our differences and acknowledging that I was limited to my own point of departure (Harrits, 2020). In addition, attempts were made to obtain closeness and reduce the immanent asymmetry embedded in the sociological research interview (Bourdieu, 1999: 609); these efforts included being flexible concerning time and suggesting interviews to take place on respondents' 'home ground'. These attempts to reduce asymmetry, together with 'being' in their lives at a very vulnerable time and for almost two years, served to build trust and establish a growing closeness. When I succeeded in coming close to participants, I experienced this success as the sharing of thoughts on vulnerable issues and an opening up to emotional reactions such as tears. A consequence was very long (focus group) interviews that bordered on therapy. In other cases, I stopped the flow of speech when it was natural to do so and directed the attention to some of the other participants in order to make space for them. However, I also acknowledge the limitations in achieved closeness, including information that has probably not been shared with me (Alvesson & Kärreman, 2005).

4.7.1. POSITIONED BY THE PARTICIPANTS

During my encounters with families and professionals, my positioning as a researcher was also crucial to the possible closeness and the quality of the empirical material constructed (Hansen & Tjørnhøj-Thomsen, 2020; Larsen, 2009). The hospital framing connected me to the health care system, but at the same time, I also stood out by not wearing a uniform, while my language usage revealed that I was not a health care professional. I presented myself and explained my presence as a researcher studying the rehabilitation courses of young adults with an ABI from an outside perspective. When encountering the young adults and their families, I underlined the fact that I was not a health care professional since I did not want to be identified as an 'expert' in NR (including in a tradition and culture that reinforced issues concerning hierarchy, power and authority) (Harrits, 2020). In addition, I also aimed to reduce possible concerns of my loyalty to eventual institutions or colleagues when discussing their experiences with the healthcare system. In contrast, I attempted to position myself as an explorative anthropologist, reinforcing their confidentiality/anonymity. In many ways, I blended in with the many professionals encountered by the families in the public pedagogical sector by being a female in my late thirties with a middle-class background, a Danish national wearing relaxed clothing (such as leggings and a long blouse) with no makeup and driving an old car. The families expressed relief in response to my offering of time, friendliness and a listening ear. This all worked towards building trust. However, family members also considered me to have a sense of ignorance in that I did not fully understand their situation; I had not experienced it in my own body.

In my experience, the professionals, on the other hand, considered me and my project with either heightened awareness (as if I aimed to control their work), curiosity, exhaustion (as an extra work task for which to summon time and energy) or most often a mix between the three. An example of the first reaction was a 'mustering' with seven professionals at an institution. I connected this with an inspection made by the

National Board of Health a year earlier strongly criticizing the institution in their report. Another example was when I asked for permission to record a discharge meeting held online; I sensed that this generated discomfort to the municipal professionals as they informed me that they would have preferred to have been asked ahead of time. I related this to their need to position me and my project and fear of what the data would be used for. In addition, I also considered that the screen created a distance that may have reinforced their discomfort. This led me to distribute written information and receive acceptance ahead of time in the following cases as well as present myself and my study more clearly to give professionals better opportunities to position me.

4.7.2. CLOSENESS AND DISTANCE TO THE RESEARCH OBJECT

Locating my office at a rehabilitation hospital, participating in the NR research unit and especially collecting my data automatically enabled me to draw closer to the world of NR, with its naturalized practices and research approaches. This closeness was necessary in order to gain enough insight into my research object of brain injury. On the other hand, it was important for me to maintain my outside perspective and hence the necessary distance to sustain my sharpened senses and avoid a level of saturation wherein new information or experiences could no longer make an impression (Prieur, 2002). I maintained this distance by continuously participating in research milieus and network groups ('Learning in the healthcare sector', 'Phlegethon' and 'Health Humanities' as well as the research milieu at the Political Science Department at the University of Aarhus while studying 'abroad') providing me with humanistic and social science inspiration. These activities have enabled me to spot issues that are unidentifiable from an inside perspective, allowing me to demystify the world of NR and break through the associated doxa with a heterodox discourse (Bourdieu, 1998).

4.8. PROCESSING AND ANALYSING THE DATA MATERIAL

Before transcribing the interviews, I listened to the audio records (sometimes several times) in combination with the fieldnotes to recall moods, emphases etc. Hereafter, the interviews were transcribed verbatim. This transcription process implies an interpretation of the spoken word (Bourdieu, 1999), where […] was used as a way to insert unspoken expressions, such as tone of voice, actions or body language. My storing, organizing and coding of the data material were assisted by the computer software system NVivo (QSR International, 2015), and a folder was made for the sources of each of the cases.

The contents of the interviews conducted with the young injured participants include expressions and statements, or their subjective expressions of the truth as they perceive it and the reasons for telling their stories the way they did (Paterson & Scott-Findlay, 2002). Hence, in this case, as with the other interviews, these contents are given distinct value in themselves in combination with my reflection, interpretation and construction of their standpoint. None of the interviews or network maps is considered in terms of its own isolated value; rather, a total interpretation of all the material is taken into consideration. The purpose hereby is to validate the findings.

4.8.1. ANALYTICAL LEVELS

The empirical data was approached and analysed at different analytical levels. A macro-level perspective was considered in paper 1, whereby the applied method was a document analysis of historical and political documents. A meso-level perspective was considered in papers 3 and 4 based on medical records, observations of discharge meetings and interviews with professionals, relatives and the injured. A micro-level perspective was the most prioritized in this thesis and was considered in papers 2, 3 and 4. This intertwining of analytical levels also constituted a verifying process, where the findings e.g. on the macro level, such as the dominant medical position in NR, were also observed at the micro level, for example, as a strong focus on the training of the individual body and its functioning observed at the discharge meetings.

4.8.2. AN ABDUCTIVE APPROACH

A rationalist epistemology concerns the inextricable link between theoretical and empirical knowledge – ‘the fusion of theoretical construction and practical research operation’ (Bourdieu & Wacquant, 1992:34) where the research object is theoretically constructed. With this close connection between theory and empirical knowledge in mind, I had the tools to prevent my research from being steered by common sense perceptions, everyday language or administrative or political conceptions (Bourdieu et al., 1991; Bourdieu, 2000). In practice, this entailed moving back and forth between theories and the empirical material, as Tavory and Timmermans (2014) suggested when describing their concept of abductive analysis. The process in practice was not as predetermined and linear as the processes presented in this thesis so far; instead, it was a circular, or rather, a messy back-and-forth interaction between data construction (observing and interviewing) desk work (theory and analysis) and text work (writing and making knowledge claims). This back-and-forth movement was steered by the overall research question concerning inequality in NR.

In preparation, I immersed myself in the data (by listening to the audio records and a thorough reading of the field notes, interview transcripts and records) and obtained a sense of the whole. Hereafter, this abductive process can be summarized in the following steps: 1) An engagement with theories of Bourdieu; 2) thematic and theory-based content coding of the empirical data, creation of network maps and observations of findings; 3) identification of patterns in the data material; 4) engagement with additional theories and more specific literature (cf. Tavory & Timmermans, 2014); 5) an adjustment of the research question to be explored; 6) a re-coding of the material and a refinement of categories; and 7) identification of findings which could not have been seen from the initial position. For each of the papers constructed, the empirical material that was selected for coding and the extent to which the phases were satisfied varied. In addition, in some of the papers, the explorative approach dominated when I was coding the material (paper 4, when constructing personal communities and PRISMs), whereas others were more theory-inspired from the beginning (papers 1 and 3). Nevertheless, overall, this approach preserved space for the creative process and paved the way for novel and interesting patterns and topics that were not expected beforehand (Tavory & Timmermans, 2014). An example of such unexpected findings was the apparent lack of clarity surrounding who was considered a relative and divergences in various perspectives discovered while coding on social capital and social burden among the relatives in the data material; these findings led to the unexpected problematizing question in paper 4, ‘Who are relatives?’, and a perspective challenging the predominant and taken for granted understandings of ‘relatives’ (Alvesson & Kärreman, 2005). This again led to the search for new theoretical inspirations – in this case, Pahl and Spencer with their extended theories on friendship – enabling us to explain our findings from a sociological perspective. A deductive phase of analysis then followed, whereby the theoretical concepts of personal community and PRISMs were applied to the empirical data to focus on considerations and perceptions concerning social relations when creating a second coding of data material. I consider this an example of the necessity to preserve space for surprising empirical findings not capturable by a single theoretical approach: ‘Theorizing is not the end but part of a process of intellectual dialogue. It is an ongoing exercise in puzzling out the world we live in, of striving for a final analysis but never completely capturing it’ (Tavory & Timmermans, 2014: 128).

The coding was conducted by the first author to enhance consistency and methodological rigour. Next, the data material was analysed from an inequality perspective and discussed with the co-authors, and the trajectories were compared and contrasted with each other and the existing literature. In addition, a continuous dialogue with NR professionals from hospitals, municipals, private institutions, research units, user organizations and political institutions (e.g. the National Board of Social Services) when presenting my preliminary results throughout my research period created inspiring ‘disturbances’ of my interpretation of the material. The knowledge produced by this research has therefore been challenged by as well as challenged the horizons of perceptions in NR. Overall, this process of qualification increased the credibility and plausibility of the findings, contributing to both knowledge on practice and knowledge for practice.

4.8.3. A NARRATIVE, COMPARATIVE AND HISTORICAL APPROACH

4.8.3.1 A narrative analysis

Through the coding process, the cases were analysed and concocted as narratives (Czarniawska, 2004; Kvale, 2008) to approximate the experiences of the families as an entry point to understanding the complexity of inequality. The narrative inspiration invited me to follow a certain chronology and stay within the vernacular. I focused on the stories told during the interviews told by different interview participants and worked out their structures and their plots. The many episodes spontaneously told and spread throughout the interviews founded the basis for the constructing of a coherent and condensed narrative. I used the voices I heard during the interviews as information to take a stance, upon which I reflected using inspiration from the literature, comparisons with the other cases and, last but not least, my theoretical influences. Hereafter, the cases were created and constructed to present my analytical findings (e.g. the trajectories in paper 3 and the social relations of the young adults in paper 4). I then moved beyond the representations of the families and professionals and broke with common-sense perceptions to construct new stories through an analysis of the different relations and standpoints (e.g. their social class belongings) in NR. Hereby, I also acknowledge that not everything is visible to the patients, relatives and professionals; this understanding encouraged me as a researcher to 'go behind' what was said during the interviews. In order to strengthen the underlying purpose of each story, details have been omitted, while other aspects reinforcing my argument have been highlighted.

4.8.3.2 A historical lens

These narratives are presented as single families' 'stories' that encompass their uniqueness, but as part of the entirety of this thesis, they also constitute a representation of inequality in NR. First, it is highly probable that other potential patients and relatives with similar dispositions and levels of capital possession will have similar experiences due to reproductive structures, as shown by Bourdieu (1984). In addition, each story is also embedded in a larger historical and social context (Czarniawska, 2004), as shown in paper 1. I therefore combine the contemporary pivotal point in the case study design with a historical approach since I believe this is integral in understanding a present-day phenomenon (Bourdieu & Wacquant, 1992, p. 90-91). This is because history exists in its embodied state as habitus and in its objectified state as fields. In other words, the empirical material constructed for papers 2, 3, and 4 has been supplemented with essential historical explanations and findings in paper 1. Thus, are captured both the lived experiences of the agents and the construction of the objective and buried structures (spaces of positions) of the social world that define the agents' external constraints and structure their actions from the inside. To give an example, a mother expressed the following at a discharge meeting:

> '…the time we spend with [the daughter] is focused on training in the interim, and we will continue because she benefits a lot from this. Nothing is coincidental with [the daughter]. A kind of a training is always considered (…) that we know she benefits from'.

During the interview with the family, the mother expressed her frustration that care at the hospital focused exclusively on the physical body rather than the mental rehabilitation from the trauma caused by the ABI. This frustration was the result of both the family's inability to set the agenda during the rehabilitation process which could be explained by patients' historical occupation of a subordinate position in hospitals. This history includes a prioritizing the individual body and its functioning, which knowledge the family uses to demonstrate their willingness to collaborate with the rehabilitation staff and ensure an improved rehabilitation outcome for their daughter.

4.8.3.3 A comparative approach

A comparative approach, inspired by the post-structuralist Czarniawska (2004), enabled me to expose dichotomies, examine silences, and attend to disruptions and contractions by focusing on patterns within and between the cases to observe unequal structures and varying handling of rehabilitation courses. A comparative approach was used to explore similarities, differences and patterns within and between the ten cases to strengthen internal validity (Levy, 2008; Stake, 1995). An example is the trajectories of three young adults studied in paper 3 (see the section on paper 3) in relation to their belonging to various social classes and a comparison thereof. This comparison required heterogeneity among the cases, which was ensured by theory-inspired coding on capital possession and conversion, agendas encountered etc. The cases are presented to demonstrate the span of my material but also to ensure a comparison with other cases.

Along with the visualizations (see paper 3), the comparative approach proved a valuable tool with which to transform the qualitative data into comparable components. Below, I insert the visualizations of three of the young adults used as exemplifications in the article, as they constitute various trajectories and class compositions. The visualizations serve as examples of how these cases have been compared and used to explain the different trajectories described in the paper:

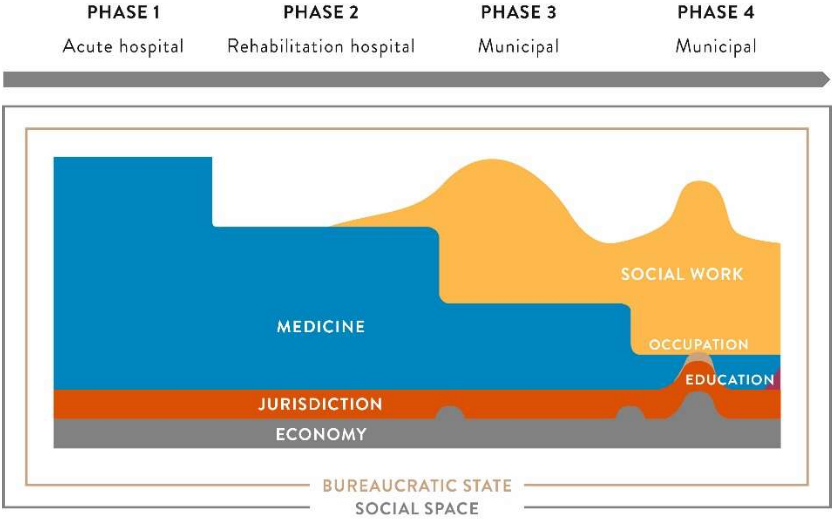


Figure 4: *Regimes encountered in the rehabilitation trajectory of Smilla.*

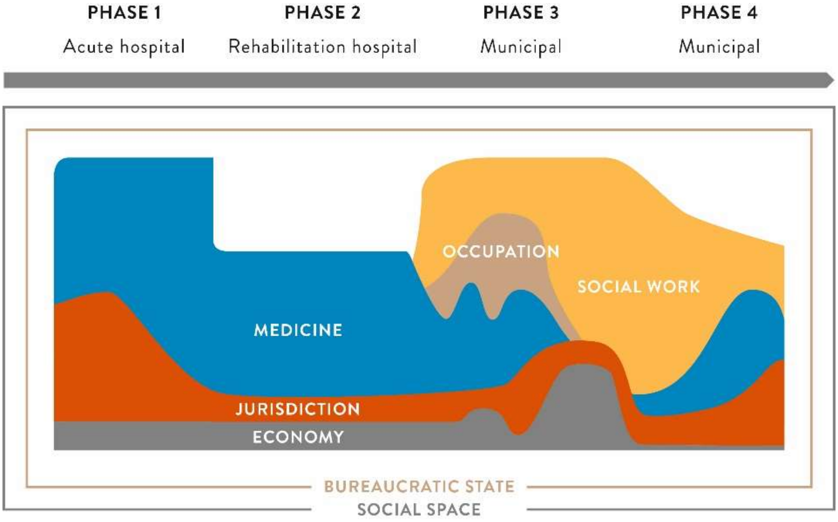


Figure 5: *Regimes encountered in the rehabilitation trajectory of William.*

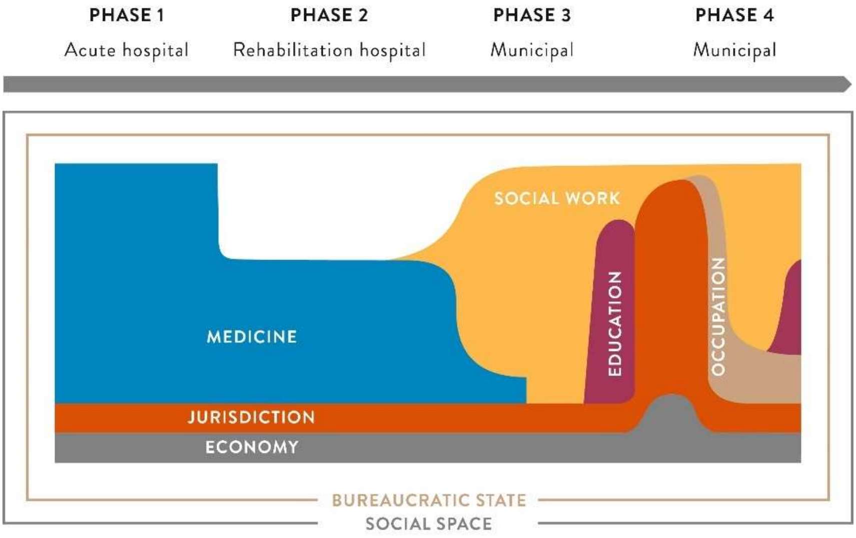
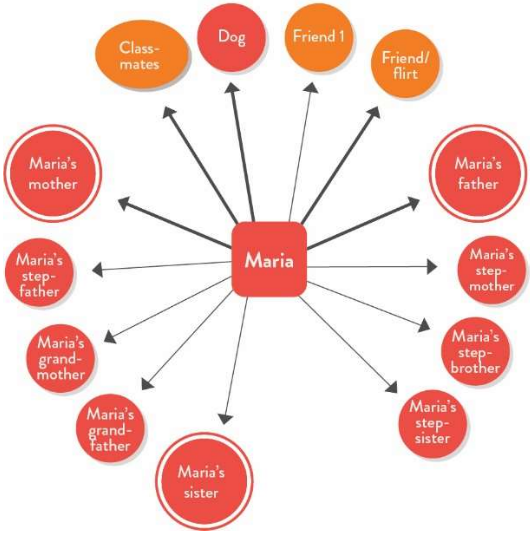


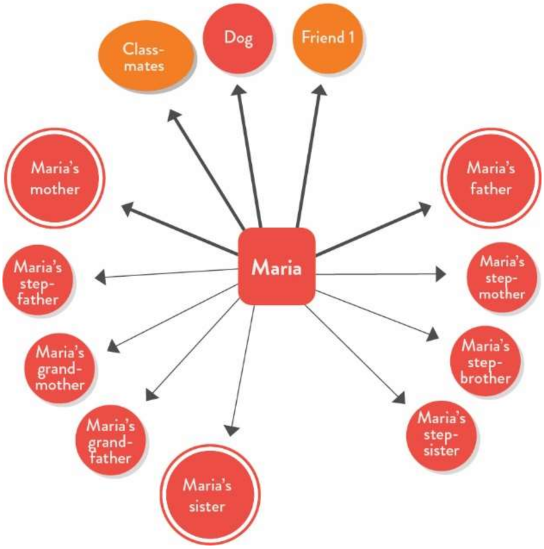
Figure 6: *Regimes encountered in the rehabilitation trajectory of Ahmad.*

In addition, comparing within the same cases was possible due to the longitudinal design that has various empirical points in time. Such an analytical approach was used in papers 2 and 4, using the network maps to examine how the social network of a young adult and/or their family developed throughout the rehabilitation process. The network map below offers an example of this comparison:

“MARIA”
BEFORE INJURY



“MARIA”
½ YEAR AFTER HOSPITAL



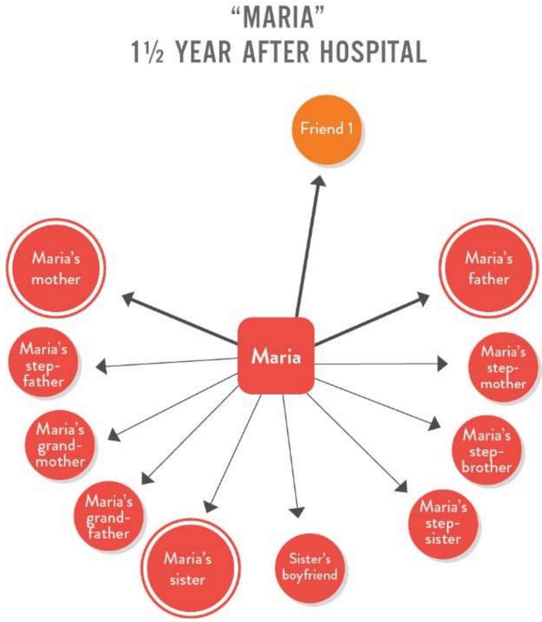


Figure 7: *Example of social network maps of Maria before injury, ½ year after hospitalization and 1½ year after hospitalization.*

CHAPTER 5. ETHICAL CONCERNS

It is not possible to reduce the ethical concerns and considerations to a single section in this thesis, rather, the aim is to permeate these concerns throughout the project and all its phases (Hansen & Tjørnhøj-Thomsen, 2020). Nonetheless, I here elaborate on several selected issues. These considerations primarily regard the included families. I entered their life at a vulnerable time and during a period with major changes. I wished to do this as respectfully as possible and without interfering more than was necessary. Many relatives expressed that it was a relief to discuss their experiences with each other and with me as an outsider who was not affiliated with their life situation in any way. However, they also expressed that having this conversation was challenging because of the many difficult emotions this engendered. Concerns introduced in this context included how to balance acting in the best interests of the young adults and relatives by introducing a minimum of inconvenience while simultaneously obtaining high-quality empirical material (Guldager et al., 2017).

5.1. Consent

Voluntary consent has been a cornerstone in medical research ethics since the Nuremberg Code after the Second World War. However, if we only include participants, we are certain are capable of giving informed consent, we lack a valuable perspective and deny the right of the disabled to participate in society, including in research (Craven, 2010; Ries et al., 2020). There is also a tendency to exclude persons with severe disabilities from research (Paterson & Scott-Findlay, 2002). However, jurisdiction fails to provide us with clear guidelines for the inclusion of persons with impaired decision-making capacity, leaving researchers in a legal grey area (Craven, 2010). Yet even if such laws and regulations were clear and consistent, pertinent ethical issues would remain unresolved (Pape et al., 2004). As my target group is young adults with cognitive impairments, I have reflected extensively on issues surrounding informed consent.

All participants (young adults, relatives and professionals) were informed of the study verbally and in writing by the investigator at a physical encounter, and written consent was obtained (see appendix B). This information described the purpose of the project, collaboration partners, confidentiality, what the participation implied, the voluntary nature of participation and the possibility of withdrawal at any time with no implications for future treatment, rehabilitation or care. For young adults with expressive cognitive difficulties, a visual and reduced version was used to obtain consent. Two young adults were unable to give informed consent, and this consent was obtained through a substitute. In all cases, this substitute was the mother, which reflected my stereotypical (Harrits, 2020) assumption that this person would be emotionally and juridically the closest to the young adult and therefore the most capable of making choices that reflected the young adult's values and preferences (Ries et al., 2020). After getting to know the families more deeply, I realized that this might not always have been the case. In five cases, a dual consent from both the young adult and the substitute (Craven, 2010) was obtained when there were doubts about the young adult understanding what I had told them or being unable to formulate additional questions, as well as when the young adults were younger than 18 and therefore had no juridical right to give informed consent. One family withdrew their consent after the first interview because of the father's frustration about me not allowing him to view the interview with his son. I felt an ethical responsibility towards the son; thus, I did not want to ask for his permission to let his father see the interview, as he might have felt forced to accept due to the father's insistence. Furthermore, I believed that the answers of the young adult (e.g. on closest social relations) might have caused disagreements between the parties. I hereby estimated that the interests of the young adult would not be safeguarded (Ries et al., 2020). This decision was discussed with and supported by the juridical department in the hospital unit. In addition, I suspected that the father wished to use the interview as evidence to show his son's decline due to a change in institution in order to demand increased rehabilitation quality. Under no circumstances did I wish to allow disconnected data material to become part of a political discussion between the family and the institution, nor did I want to submit to such a 'threat' (Hansen & Tjørnhøj-Thomsen, 2020). With the benefit of hindsight, this might seem an easy decision, but in reality, it was difficult because of the confidence and gesture I had been shown by the family when I interviewed them. The empirical data constructed before the family's withdrawal is still included as part of the data material in this thesis, in line with the Data Protection Act (GDPR, EU), article 38.

As my study has been qualitative and explorative, the topic of analytical exploration was not initially planned for inclusion. Therefore, a full presentation of the research project has not been possible for the included participants. An example is inequality developing as an overall theme with a strengthened focus because of my participation in sociological research milieus. Because its importance increased over the course of the study, this topic was only presented indirectly to the participants. In addition, informed consent is indirectly based on an underlying assumption of the research person as an autonomous person who can fully understand the consequences and decide freely without constraint. However, this disregards the fact that both the participant and the researcher are embedded in pre-existing social and cultural contexts and ignores the given difficulties of explaining the exact nature of the research process. I hereby deduce that informed consent is not only a matter of outside situated formalities to be complied with but also an ongoing process formed by the values guiding the research. This is due to the near impossibility of the families fully understanding the academic analysis, as highlighted by Bengtsson (2019). She argues for the need to actively acknowledge the power relations that young people's lives are part of and that our research is embedded in to understand the ethical implications of a project. In my case, the unequal power relationship was highly relevant because of the patient's young age and their vulnerability and cognitive impairment, including memory loss, entailing a need to reconceptualize the informed consent for each encounter. In practice, this entailed me explaining to the young adults why I was there and asking whether they were okay with me observing and/or interviewing them. Hereby, process consent was used for ongoing checks of their willingness to participate (Ries et al., 2020). I experienced that one of the young adults was not comfortable with me interviewing his family and what they said about him. I used transparency as a strategy in order to demystify what we discussed by showing him the interview guide and stressing that our focus was on their life situation and not his.

In practice, I experienced very few concerns from the families about the purposes of my project and the formalities concerning consent. I trace this back to their preoccupation with uncertainty and significant unanswered questions about the future due to the unknown functionality of the young adult. This left little room for issues that did not relate to their own needs and concerns. Participating in this study was therefore only of minor interest and linked to their trust in me (and the professionals helping me to establish the contact) rather than the information that I had conveyed about the study.

5.2. DATA HANDLING

All the data material was handled confidentially and stored safely according to Danish law, both physically and electronically. The interviews were transcribed, whereby for approximately one third of the interviews, I had assistants helping me. These assistants were introduced to the project and correct handling of the data material before signing a declaration of confidentiality. All the interviews were listened to several times in combination with reading the notes of the observations in order to catch and remember nuances and to enable me to recall details in terms of the atmosphere, tone of voice, body language etc.

During the transcription and in the presentation of the cases, all the material has been anonymized; however, nuances are maintained to ensure credibility. As a result, the families would probably recognize themselves. Pseudonyms are used for all places, persons and institutions. Due to the small number of young adults with an sABI, I have also made substantial changes such as sex, age, region etc. in order to confuse any reader with knowledge from the field and a certain person in mind and thus avoid recognition. I have also reflected on the fact that exposing the families in such a way might be perceived as offensive e.g. by the families themselves as a result of the presentation being different from their own perception. This reflects the ethical challenge related to a praxeological research approach containing an objectivation of the subjective, which is an ethical challenge in itself since the (re)presentation of the analytical findings can, on the one hand, be meaningful to the participants but also, on the other hand, seem obscure or perhaps even offensive. Hereby, it has never been the purpose of the project that the participants should be able to comprehend or verify the findings or representations. Nevertheless, I as a researcher have struggled with the ethical premise of presenting someone as low positioned, underclass or vulnerable.

The latter might also be the case, for example, in the designation of family structures when constructing these in relation to social capital, where terms such as weak, strong and vulnerable family structures were used. I will explain and argue for these terms through the use of a theoretical sociological language (highlighting that the terms are not to be understood as everyday terms), e.g. those derived from SNA. This balance between the everyday language used with the participants and the sociological theoretical objectivation in general caused unavoidable ethical dilemmas. A tool used to balance this, inspired by Prieur (2002: 153), was to read the text before publication without anonymization and to consider if I would maintain the meaning of what was written. This entailed a few adjustments of the text.

5.3. ASPECTS ON CONFIDENTIALITY

I realized that issues of confidentiality were challenged when the long in-depth interviews were conducted with the families, young adults and professionals. This was due to the substantial knowledge I gained of the situation of the injured individuals from various sources over a long period of time. An example is my interview with one of the young adults, who told me about his sister who had recently being diagnosed with a serious illness. I used this information to initiate the topic while interviewing the family. The sister, unperturbed, responded to me by telling me about it in detail. Although the interviewees didn’t seem to notice, it was still very unfortunate and something I continuously reflected on and tried to avoid.

Another ethical reflection arose when I interviewed the professionals about their perception of the family’s resources in order to explore various capitals from different perspectives. When asking such questions, I experienced them being uncomfortable, which I interpreted as a feeling of being disloyal to the families due to strong ethical concerns as a basis and practice, e.g. as taught through their education. This appeared to result in an exaggerated positive presentation of the families, as the accounts professionals offered in interviews were at least to some extent driven by the interest to uphold specific versions of how social reality should preferably be understood (Alvesson, 2003). I therefore avoided asking about their perception of the family’s resources directly in the following interviews and instead tried to approach it more indirectly by asking for elaborations when something related to this topic was addressed.

The families were, when entering the project, asked whether they wanted information on the results of the project. If they signed up for these results, they will be sent an abstract written in layman’s terms as well as links to the publications immediately after the PhD defence.

Due to the sensitive personal data that the design involves, this project was reported to the Data Protection Agency under the case number 1-16-02-552-15. The committee of Health Research Ethics was contacted and it was here clarified that approval was not needed because no experiments or interventions were involved.

5.4. FUNDING AND CONFLICTS OF INTERESTS

The study was initially funded by a Central Region Denmark project titled Lost Dreams – New Hopes (BD-NH),[26] which received funding from the Ministry of Health and Prevention in order to strengthen the national effort to target young people with an ABI. The PhD project also received funding from the Health Research Foundation of Central Denmark Region grant number R5-A322. The project of BD-NH set the overall framing design of the study, such as age group, the severity of the ABI and regional demarcation. Apart from this, these funding institutions have at no point interfered with the process, methodology, choice of theory or any other elements that might raise the question of a conflict of interest.

The four papers (including the book chapter) have been exposed to blind peer review before publication. The authors have agreed on the order of authorship and who should be the primary partner for discussion. The contribution of each of the authors to each paper has been clarified in the attached co-authors' statements.

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[26] The Danish Translation is 'Bristede Drømme – Nyt Håb' (BD-NH) and is a project that ran from 2013 to 2017.

CHAPTER 6. REFLECTION, DISCUSSION AND PERSPECTIVISM ON THE PAPERS

A brief summary of the papers was presented in chapter 2. I will now present the reflections made during or after the writing.

6.1. REMARKS ON PAPER 1

6.1.1. VISUALIZATIONS – AN ANALYTICAL TOOL

Bourdieu himself used visualizations in his work to explain his texts. These varied from correspondence analysis based on statistical material (Bourdieu, 1984) to more loose drafts. Also, other researchers such as M. Savage (Personal communication[27], 8th August 2018) have argued for the increasingly crucial role of visualizations for researchers to create compelling narratives. Inspired by the field of cultural production (Bourdieu, 1996), the figure in paper 1 consists of a visualization of NR and its demarcation to the surrounding fields in social space at two different times: 1980 (when emerging ideas were institutionalized) and 2007 (after the municipal reform). This figure was created to compare the differences in autonomy and demarcation between NR and other fields, where I, e.g., demonstrate that NR has increased in size due to more survivors and better treatment possibilities in recent years. The surrounding fields are constructed in terms of volume to reflect their estimated influence on NR. These estimations are based on other researchers' studies on user organizations for the disabled as a political actor (e.g. Bonfils, 2006; Storgaard & Bangshaab, 2012), the formation of rehabilitation (Feiring & Solvang, 2013) combined with powerful political documents, such as legislation programmes from National Board of Health, that were analysed. In line with Bourdieu (Bourdieu, 1996), this meta-figure is not based on statistical data (specific indicators of types and volumes of capital); rather, it is a reflection of the analysis and hence a synthesis of the possession of capital by the primary agents and authorities as well as their involvement and success with setting the agenda within NR. In other words, the figure only serves to create an overview and visualization, providing a respite from the text. Hereby, it is not possible to compare the fields in exact size and composition.

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[27] Presentation at the PhD course "Theoretical and methodological challenges to the study of rising inequalities"

In general, the figures have become a helpful tool in my work process, and the layout of the figures in the thesis has developed throughout the PhD process. The figure with a refined layout (compared to the one in the published paper) is inserted below.

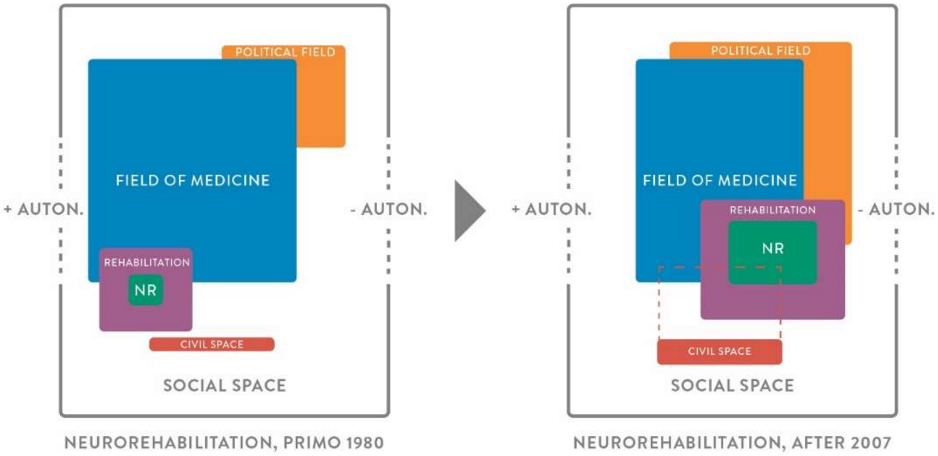

Figure 8: *Renewed figure of NR in the beginning of the 1980s and after 2007*

6.1.2. Contemporary and future tendencies

NR, as shown in paper 1, is simultaneously an area of constant development surrounding its practice, research and politics and also characterized by a certain level of inertia and stability, e.g. connected to the positioning of the agents. The development of NR is e.g. driven by a body of new political documents, a significant contribution to which was published after the writing of paper 1 (National Board of Health, 2020). This reflects the continuous specialization, standardization and centralized political steering of NR. Rather than continuing the analysis of documents from paper 1, I will merely offer several reflections on the basis of the report by the National Board of Health (2020) in order to follow up on the line of inquiry drawn by the previous analysis. The disease management program reflects an extended heterogeneity based on the number of agendas, legislations and agents represented as well as the collaboration between these; the primary appointed agents belong to health care, social, employment and educational departments. This also entails an increased focus on collaboration between sectors and a political acknowledgement of the many and different political agendas (hence doxas) encountered during a rehabilitation course; with the findings of paper 3, I contribute to this understanding with an empirical unfolding thereof. In addition, the new publication expands the traditional medical focus on the individual body and its functioning as the pivotal point for rehabilitation to a perspective in which patient and relatives are considered collaboration partners and engaged through dialogues, systematic involvement etc. (National Board of Health, 2020 e.g. p. 25). I interpret this as the tone being set for a deflating of the traditional hierarchy characterizing the medical field, where the doctors possess the legitimate knowledge and the patient is a passive recipient of treatment. This also entails a higher positioning of relatives as a group of people to be given distinct attention in the form of accommodating their needs (National Board of Health, 2020 e.g. p. 26-28). To sum up, there is an increased focus on collaboration in NR, with an expected rise in attention given to life aspects beyond the individual body and its functioning as well as an expanded perspective that, in addition to centring the individual injured body, also offers relatives greater consideration. Nonetheless, as also argued in paper 1, I expect a certain level of inertia and stability to remain in the field because of the inherent structures in its material, institutional and bodily forms that influence both perceptions and actions. In other words, such political announcements might still be far from being transformed into practice.

6.2. REMARKS ON PAPER 2

From a critical perspective, it should have been explicated in the paper that the data used for constructing the social capital of the family also contained answers from the surveys concerning help/support. In addition, it would have been preferable to include available data from the injured individuals in this paper to consider reciprocity and a larger family network perspective.

6.2.1. DISCUSSION PATHS

A discussion on the results of the paper in comparison with other studies would have opened up the possibility for further relevant perspectives. I will highlight a few relevant ways in which to proceed. The first course of action is to discuss the results in conjunction with Granovetter (1983) e.g. showing that social systems lacking in weak ties will be fragmented and incoherent. Such a discussion might call into question my results which suggest that a strong close unit is advantageous in a rehabilitation context. This incongruity might be explained by variations in the studied fields whereby a job situation differs from a very serious illness situation. However, this discussion also bridges the findings of paper 2 and 4 (see the findings of paper 4 showing that a reduction of the larger social network of the patient at an early stage may have long-term consequences.

Another interesting perspective to further explore and discuss concerning social capital is negative social capital (Portes & Landolt, 1996). Such a perspective would offer a more balanced picture of social capital. An example found in my empirical material is conflicts occurring when relatives/social network relations strive to exclude each other in order to be the ‘first relative in line’. This demonstrates the negative impact that a social network can have on one’s life if it is characterized by mistrust, hassle, criticism, and domination (Heaney & Israel, 2008). Relatives can also draw the patient in directions not recommendable by professionals, such as drinking alcohol, leaving the young adult with a dilemma. In addition, the roles of patients and relatives might be intertwined since being a close relative to a person with an sABI can in many regards entail a burdened life (Gan et al., 2006; Sander et al., 2002), making relatives possible patients themselves. Since people in close relationships are often distressed by the same stressors, the injured might therefore be affected by such distress (Gottlieb & Wagner, 1991). Also, the relatives are concerned with the well-being of the injured, but when such caregiving attempts are not well received or do not result in positive changes in the situation of the injured, the helper can react negatively (Glanz et al., 2008). Methodologically, this inquiry would include a specific focus in the interviews and/or a survey with questions or a name-generator of difficult or negative relationships to recognize these as an important part of the ego’s social world. This is e.g. addressed and experimented with by Straits (2000).

In addition, an earlier consultation with the work of Atkinson (2012; 2014) would have also provided me with terms enabling me to refine the terminology, e.g. ‘split family structure’ as used in paper 2 could have been relabelled ‘dispersed family structure‘. This theoretical contribution, which considers families as a field (Atkinson, 2014) with an internal hierarchy, would have offered an interesting approach in paper 2 in order to further explore internal struggles, doxas and dynamics.

Possible further exploration of social network support has also been addressed in the section: ‘Future possible research paths’.

6.3. REMARKS ON PAPER 3

6.3.1. Empirical material

Visualizations are used as a methodological tool to create an overview of the many regimes apparent at various times during a rehabilitation process. Hereby, it should be underlined that such figures are based on my qualitative interpretation of the data material available, including an expectancy when empirical holes occurred. These visualizations provide me with the possibility of comparing the trajectories, as described in the previous section on processing and analysing the data material.

6.3.2. TRAJECTORY

In this paper, I employ the term ‘rehabilitation course’ to describe the chronology of rehabilitation which has been organized and standardized beforehand from the outside, e.g. as defined by the Danish Health Authority (2011a). I also use the term ‘trajectory’ as an analytical to describe the given probability of various families taking a certain path through rehabilitation reflecting their social class and leading them to given positions. These paths lead them to given positions. This understanding of the concept is inspired by Bourdieu (1984) both acknowledging the uniqueness of habitual dispositions but at the same time including general possibilities and challenges among social groups with comparable dispositions. Hereby, a rehabilitation trajectory is not only characterised by ‘choices’ made by the families but is also to some extent given beforehand. This is reflected in Bourdieu’s physician and military terminology: ‘flying on above his real trajectory like a projectile carried on by its own inertia’ (Bourdieu, 1984: 150). This perception of trajectories also suggests an expected similarity in the ways individual trajectories develop in response to other social or health incidents such as occupation (Bourdieu, 1984). Such trajectories, grounded in sociology, has been studied by Atkinson (2012) concerning social space travels caused by education and by Spencer and Pahl (2006) concerning friendship trajectories. These similarities are demonstrated in rehabilitation trajectories through parallels between trajectories among families with similar dispositions. In line with this, a Danish study on NR addresses how dispositions create facilitators and barriers for involvement during hospitalizations (Guldager et al., 2019).

Reflections were made before this determination since trajectories is a term used in the literature of both health care and sociology. In the health care science literature (e.g. Arntzen et al., 2015), trajectories are used together with concepts such as pathways (e.g. Sveen et al., 2016) and courses (Schönberger et al., 2014). In this literature, however, it has not been possible for me to track clear reflections concerning the choice of the term, and it seems as if these concepts (rehabilitation courses and trajectories) are largely used as synonyms.

6.4. REMARKS ON PAPER 4

6.4.1. Connection to paper 2

This paper has a direct line to paper 2. However, paper 4 has a longer time span since data gathered 1½ years after discharge is also included. In addition, a change in focus from paper 2 has occurred; while paper 2 focuses on the conversion of capitals in a rehabilitation context, paper 4 is concerned with the engagement of social relations during rehabilitation and the consequences of social network relations from a wider and more long-term life perspective. By combining the results from papers 2 and 4, it becomes clear that the family structures and strategies beneficial for acquiring rehabilitation services (a strong, closed family structure, as found in paper 2) are not the most advantageous from a longer social life perspective, while a larger social network and various relations (rather than exclusively parents and siblings) might be crucial in other regards. I hereby find that the strategy of closure around the small family unit (as found in paper 2) expectedly has the price of a reduction of an injured young adult's larger social network and, with it, the risk of long-term social isolation for both the relatives and the young adult.

6.4.2. A REPRODUCTIVE PERSPECTIVE

The paper's link to inequality is explicated only briefly; nevertheless, this link still permeates the paper, as its reproductive structures are embedded in concepts of 'perceptions' and 'PRISMs'. I will include several clarifying remarks on this to present a clearer connection to the overall theme of inequality in this thesis. This theme exists in both professionals' reproduction of idealized and internalized mental models in society regarding which people are perceived as relatives and the study's unintended reproduction of this perception through the recruitment of participants to this research project. It can be assumed that the professional reproduction of these models is rooted in perceptions of who is to be considered a relative, which to a certain extent are shaped by the perceptions of a collective and well-founded illusion of the family as a social category existing within us all (through mental categorizations and schemes of perception) and supported by the state through politics, such as tax, housing and social politics (Bourdieu, 1998). These perceptions persist despite the parallel existence of other family forms. This collective illusion is acquired through, for example, the educational socialization within the welfare state profession as well as the institutional rehabilitation context with its overall ICF principles as the guiding framework (Marselisborg Centre, 2004). However, in response to these collective illusions as well as social science estimations on how individualism might erode solidarity, our study argues for the acknowledgement of other types of relationship (in addition to the family) disembedded from time, space and blood ties. I hereby question rehabilitation models and interventions directed only at families (e.g. Foster et al., 2012; Soendergaard et al., 2019) that do not consider larger social networks or the dynamics thereof throughout a rehabilitation trajectory.

When mentioning this research project's unintended reproduction of common-sense perceptions of who relatives are, I refer to the inclusion of participants in the project. In this study, a professional pointed out the closest relative of the young adult. Hereafter, this relative (together with the young adult if possible) pointed out the other relatives invited to participate in this study. This inclusion approach, I presume, might have led to a reproduction of PRISMs, thus limiting the number of relations and the perception of which individuals should be appointed relatives. This dynamic was not visible to me until the writing of paper 4 exemplified how the (re)production of inequality takes place unnoticed even when studying this phenomenon.

6.4.3. CONSTRUCTION OF THE OBJECT

The topic of this paper emerged very late in the process (during the process of analysis), entailing methodological and informational post-reflections. One reflection is that it would have been rewarding to further nuance and more directly explore the perspectives of the professionals and relatives concerning the determination and consideration of who they perceive as relatives, including their reasoning. This would have involved interviewing the professionals from the rehabilitation hospital instead of 'only' deriving this perspective from the medical records.

I note that the young adults' injury severity doubtlessly affects social ties, especially in the long run, since it has a major impact on the interaction possibilities as well as their ability to share activities and interests. In this paper, severity has not been used as a factor explaining the reduction in the personal community both because it was not interpreted as the primary explanatory factor and due to the need to highlight other aspects of relative engagement and perception. Nonetheless, it is most likely that severity is crucial in impacting an individual's ability to maintain social relations in a life with a disability, to what extent it is possible to interact, and the level of care needed. This paper points to the need for an activation of a larger social network without discussing which roles such a network should take and in which situations it should be activated. The size, roles and activation situations of larger social networks are expectedly closely linked to individual needs as well as the severity of the ABI.

CHAPTER 7. CONCLUSION AND IMPLICATIONS FOR PRACTICE

The thesis has explored the mechanisms behind inequalities in NR trajectories from a renewed and innovative approach by combining theories and alternative empirical approaches and the researchers' reflections to constitute an interactive whole. This approach contributes a piece of the puzzle of understanding inequality in the welfare state through the response to my overarching research question:

How is inequality (re)produced in the rehabilitation trajectories of families with a young adult who has acquired a severe brain injury?

I start by answering each of the four work questions under four concluding headings processed in the four papers. Thereafter, I finish by summarizing the points and produce a final response to the overall research question.

7.1. BIOMEDICAL SEDIMENTS IN CONTEMPORARY REHABILITATION

How can NR be understood from a sociological field perspective to illustrate framing structures and dominant positions shaping the practices? (primarily answered in paper 1).

Neurorehabilitation is an area of constant development related to practice, research and politics and has undergone major transformations since the 1970s. Overall, my analysis showed that NR is a multi- and interdisciplinary practice characterized by heterogeneity in practices, cooperation between sectors and an improved positioning of patients and relatives. Conversely, there is a growing homogeneity in clinical practice due to an increased number of NR institutions and, in later years, political guidelines driving a formalization of treatments that has been evident over time. Despite NR's status as a multi- and interdisciplinarity practice, traditional medical principles prioritizing the individual body and its functioning as the pivot point for rehabilitation are still dominant. This power is performed through an alliance with political institutions and reflected in doxa.

7.2. FAMILIES’ ZIGZAGGING TRAJECTORIES

How and why do trajectories after an acquired brain injury vary and which resources are required when families are struggling with serious injuries in and between different institutions? (primarily answered in paper 3).

When an individual acquires an sABI, the rehabilitation process is demanding and entails a high level of complexity due to the many different kind of impairments causing various regimes (including cultures, logics and agendas) encountered by the families, such as medicine, social work, education, occupation, economy and jurisdiction (see figure 1). In addition, the rehabilitation services offered by the welfare state systems vary depending on e.g. regional and municipal belongings. The ability to navigate this process and overcome barriers was tied to social class belonging, including possession and conversion of capital and the ability to match the doxas encountered in rehabilitation. The capital forms primarily identified as transmutable were cultural health capital, social capital and bureaucratic capital. In contrast, economic capital seemed less predictive for the families, which might be explained by the extensiveness of the welfare state providing free-of-charge rehabilitation services.

7.3. SOCIAL CAPITAL – AN AMBIGUOUS CHARACTER

How is social capital invested and converted during the process of rehabilitation and how can this be used to explain inequality? (primarily answered in paper 2 and 4).

Social capital was shown to be advantageous in a rehabilitation trajectory. Families with a strong, closed family structure were the most successful in transforming resources, e.g. due to their cooperation with professionals. This family structure was characterized by resources being concentrated among close cooperating family members, which was subsequently transformed into cultural capital in the rehabilitation process, reaping greater benefits in terms of advantages, preferential treatment or additional services from the welfare state. However, the small and weak family structure and the split family structure were the least beneficial to individuals in the rehabilitation processes. These network structures were associated with a low degree of negotiation and cooperation between the family and service professionals and left the families with little influence on the rehabilitation process and their own life situation. However, the family structures and strategies beneficial for acquiring rehabilitation services were not the most advantageous from a longer social life perspective; on the contrary, a larger social network with various relations (not only parent and siblings) was correlated with a positive social life in the long term. I found that the strategy of closing around the small family unit expectedly led to a reduction of a larger social network and, in turn, the risk of social isolation for both the relatives and the injured young adult in the long term.

7.4. WHO IS A RELATIVE?

Who is considered a 'relative' during rehabilitation and how can a sociological theorizing of 'relatives' be an entrance to study inequalities? (primarily answered in paper 4).

In the previous section, I concluded that relatives (in the form of social capital) are important from an inequality perspective when an individual acquires an sABI. However, the question of who constitutes a relative remains largely unresolved. I find that relatives included during the rehabilitation process are based less on the young adult's perceptions of their close network ties than on those of the professionals and, to some extent, the parents. This might result in a reduction of the young adult's larger social network which impacts the size and strength of their personal community in the long run. I hereby conclude that rehabilitation institutions play a decisive role in an individual's ability to maintain a social network, even after rehabilitation. In addition, I suggest an expansion of the term 'relative' to include other social ties as well as a consideration of these ties as dynamic in character throughout the rehabilitation course.

7.5. Inequality in neurorehabilitation – conclusion and implications for practice

Finally, I sum up and answer the overall research question in combination with highlighting the practical implications:

How is inequality re(produced) during the rehabilitation trajectories of families with a young adult who has acquired a severe brain injury?

When an individual acquires a sABI, rehabilitation entails institutionalization for a long period of time, wherein the focus is centred on the individual body and its functioning. This arrangement entails living in a social bubble with limited access to one's social relations from before the injury. These conditions impact individuals' ability to convert social relations to social capital, which is crucial for the acquisition of rehabilitation services and the overcoming of challenges and diversities in the rehabilitation process. The rehabilitation process following an sABI is highly demanding due to the many regimes with appurtenant agendas involved as well as the unequal distribution of services. Social relations can provide access to other capital forms, such as cultural health capital and bureaucratic capital, which are crucial to navigating and bridging diversities and challenges met. These forms of capitals can hereby ease the learning process when individuals and their families are socialized into the world of NR. Throughout this learning process, success is closely related to social class. However, social relations are not only crucial in relation to the rehabilitation process but might also be decisive for the long-term social life consequences of the injured individual, as they are crucial for the (re-)establishing of everyday life and hence the avoidance of social isolation. I suggest to consider ‘relatives’ as a dynamic concept which must be widely prioritized and reconceptualized throughout a rehabilitation course to impend risk of diminishing in the individuals’ lives. In this regard, rehabilitation institutions, which are represented by various professionals, play a crucial role in the engagement of social relations. This role clashes with a historical, cultural and political prioritizing of the individual body embedded in the organization and professionals’ models of perceptions. Thus, an injured individual with more fragile social network relations who needs support to maintain or even expand this network might be disadvantaged compared to the injured individual with a more solid network who can activate social support on their own. The social gap between injured people might hereby increase throughout the rehabilitation course and reinforce more general inequalities in the Danish welfare state.

7.6. SCIENTIFIC CONTRIBUTION

At the beginning of this thesis (‘Background’ and ‘Framing the researcher and the research project)’, I positioned myself in relation to the worlds of both NR and sociology. I consider this thesis a contribution to both of these worlds, and in the following subsection, I clarify how I view this contribution.

7.6.1. SOCIOLOGICAL CONTRIBUTION

- Research on inequality is largely dominated by epidemiological research (see the section on Illness inequality in the Danish welfare state). Such studies contribute valuable knowledge, documenting social inequalities in health. However, a focus on individualistic behaviour and choices (agency) that considers the subject as sovereign and enlightened permeates these results. My research study (especially papers 2 and 3) contributes to this body of research by studying inequality in rehabilitation as a contextual, social and dynamic process whereby immanent and framing structures are also considered. Hereby, the lived experiences of patients, relatives and professionals are combined with the construction of objective and buried structures in NR. In addition, my qualitative approach unfolds the concrete aspects of inequalities and highlights reproductive factors to explain how such inequalities are (re)produced, thereby supplementing the statistical research.

- I consider this thesis a contribution to the theoretical construction of family and friends contextualized by illness. This empirical exploration nuances facets of the discrepancy between the idealized understandings and the set of relationships in which the young adults are actually embedded. I further develop the theoretical concept of personal community – a term that has been developed for people and various life-phases as part of a more general understanding. In this thesis, I show how this concept can advantageously contribute in an illness context when studying 'relatives'.

- Combining the theories of Bourdieu and Pahl and Spencer creates a renewed framework to explore how the social relations of young disabled persons in contemporary society can be connected to inequality. This combination enables me to approach the characteristics and functions of social relations as well as include framing and reproductive structures in the trajectories of rehabilitation. Hereby, I have employed an eclectic approach in order to comply with new paradigmatic perceptions of phenomena as complex where isolated scientific disciplines or theoretical approach might have fallen short.

- I point to QSNA as an innovative entrance to study family units and dynamics and transformation over time when illness occurs. Hereby, I outline a methodological framework to operationalize and empirically explore significant social relations.

7.6.2. CONTRIBUTION TO NEUROREHABILITATION

- This thesis contributes to the upcoming pole of research that considers NR from a holistic perspective with a particular focus on social life perspectives. Hereby, attention is given to aspects of rehabilitation beyond the individual body and its functioning.

- Relatives (or related concepts) are increasingly considered in rehabilitation. This thesis invites reflections and discussions on the perceptions and engagement of relatives. I propose a dynamic perception of the concept and a longer perspective on the engagement of relatives. Such a perspective considers the possible support that a larger social network can provide both during various rehabilitation phases and when (re-)establishing everyday life. Thus, I challenge rehabilitation models and interventions that are directed at the families and which do not consider an individual's larger social network or its dynamics throughout the rehabilitation trajectory. A framework that includes this larger social network enables professionals to recognize existing and potential resources of social support as well as elements of personal communities that are fragile or fractured.

- My longitudinal design gives insight into the rehabilitation trajectories of young adults over time, capturing critical transitions in rehabilitation and changes in the lives of the families (life transitions, status transitions, and the mundane transfers across institutions and sectors). This knowledge cannot be captured by the numerous rehabilitation research studies which focus on a single point in time or consider a shorter time span to study a specific component of the rehabilitation process.

CHAPTER 8. PERSPECTIVATION OF THE FINDINGS

This thesis explores different facets of the post-sABI rehabilitation process from an inequality perspective. I now discuss the transferability of the findings to other research contexts, practice and future possible research paths.

8.1. THE UNIQUENESS OF NEUROREHABILITATION – TRANSFERABILITY AND EXTERNAL VALIDITY

Transferability refers to the possibility of transferring the results of the research to other contexts and the question of whether these results are limited to NR.

The engagement of relatives and the consideration of relatives as a transformative source in an illness context is not unique to NR, as these elements are also prominent in other illnesses, such as cancer rehabilitation (Applebaum & Breitbart, 2013), psychiatry (Eckardt, 2016) and dementia (Brodaty & Donkin, 2009); in these contexts, relatives are strongly considered and also, to some extent, supported at an early stage of the illness. However, there may be different requirements of who is considered a relative depending on the illness severity or chronicity or the character or age of the ill individual. Here, I expect the largest transferability from NR to illnesses characterized as chronic, life intrusive, personality-changing and deeply consuming not only for the individual but also for the closest social relations surrounding the 'ill' person, and where the relatives play an active role in the everyday handling of the illness. In addition, the findings of this research are closely related to the age of the patients, creating certain issues worth considering when the findings are transferred to other illnesses.

The results in this study have been gathered from a relatively small number of participants and in a local context constituting specific requirements at a specific time in history. As a result, no claim is made of exhaustiveness. In addition, I represent a research tradition in which the researcher is to a large extent a co-producer of the results; this approach entails an impossibility of replicability, as these findings could not be reproduced with the replacement of the researcher with another person. However, according to J. Pols (2015; Personal communication, 4th March 2021)[28], this replicability is not desirable, as studies characterized by specificity must be

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[28] Presentation at the international conference "Chronic living - quality, vitality and health in the 21st century" 4th-6th of March 2021

transported to other contexts by comparison rather than through attempted generalization. To increase the possibilities of comparing and thereby transporting the results to other illness categories, I have striven for transparency by providing rich contextual information (e.g. as provided by paper 1), detailed methodological information, examples of how the analysis was conducted and considerations of the choices made (hence my adoption of a reflexive position as a researcher). In addition, I have also avoided, in line with case study researchers (Ramian, 2012; Stake, 1995) applying generalizations to a larger population; instead, the theory forms the discussion partner also concerning cogency of the study and allows a larger statement of the results to be made. Instead, I leave it up to the reader to develop an analytical generalization and convert the results to other contexts (Guba & Lincoln, 1994; Kvale & Brinkmann, 2009).

A concrete example of this lack of generalizability appears in the three family structures presented in paper 2. I here make no claim that these constitute all possible family structures; rather, the intention is to reveal patterns in the accumulation of family capitals and strategies that can be converted to benefits within NR. This indicates that more family structures expectedly exist and that different family structures would possibly have appeared with a different population, a different illness, a different institutional context, and e.g. 50 years ago, since family structures change over time.

8.2. CONVERTING THE FINDINGS TO PRACTICES – IMPLICATIONS AND CHALLENGES

Challenges with converting research to rehabilitation practices have been addressed by researchers with explanations such as clinicians always having the skills, authority, knowledge or resources to be able to translate the findings from a research trial and apply these in clinical practice (Lynch et al., 2018) and the need to re-localize suggestions to make them work in new practices (Pols, 2015; Kristensen & Hounsgaard, 2013). Expectedly, these challenges are greater for non-interventional study designs, such as that of this thesis, since the study did not include any practical experiences with a concrete intervention form. Nevertheless, a strong motivator both for me as a researcher and expressed by the participating families is to contribute to rehabilitation improvements for young adults with an ABI in the future. I, therefore, draw attention to the need for practical experiences with professionals to support the coordination of the health care systems crossing barriers such as sectors, legislation etc. in order to compensate for relatives (Høstrup & Høgsgaard, 2018) who lack possession of the required capitals. This requires a freer form of intervention than is typically found in the Danish health care system, with the ability to cross municipalities (e.g. if the young adults move from one municipality to the other or parents are residing in one municipality while the young adult is in another) and sectors (since a rehabilitation trajectory/course crosses sectors and continuity is preferred) (Slomic et al., 2017; Sveen et al., 2016). However, this is not only a practicality but also a form of intervention, considering the emotional and social life challenges that a family with a young member with an sABI goes through. Therefore, such an intervention should not be limited to the injured person and hereby tied to a civil registration number. Inspiration for a social network intervention could be found in Siegel et al. (1994) concerning the support needs of people with long-term mental health illnesses. This framework incorporates three broad approaches to social network intervention: Building new network ties, maintaining and strengthening existing ties, and enhancing family ties. Such an intervention form relates to a larger group of relatives, which for the target group studied in this thesis could include classmates, leisure activity friends, employers etc. To address the findings of paper 4, such intervention should also include a definition of relatives as dynamic.

On a practical interventional level, inspiration for an intervention could be found in the youth mentor service for people with an ABI in Central Region Denmark. The purpose of the youth mentor intervention is to support young adults experiencing this life phase in dealing with family, friends, education, jobs and leisure activities in combination with navigating their ABI. This youth mentor intervention in many regards differs from traditional welfare state intervention forms by being more ‘free’ in its framing (e.g. enabling collaboration across municipal and sectorial boarders, including dialogic methods with the young adult setting the agenda, and considering the young adult and their family in their totality rather than using an individualistic approach), enabling them to follow the same families for a longer period of time. This intervention expectedly compensates for limited resources in some of the families.

However, I expect possible challenges to the legitimation of such intervention forms due to opposing political tendencies within the competition state (Pedersen, 2011) and its neo-liberal perception of public services as price-value products and responses to short-term symptoms instead of preventive long-term approaches (Høgsgaard, 2018; Søgaard, 2018). Larsen (2016) problematizes – from a Bourdieuan approach – how the right-hand state (the masculine side of the state, e.g. represented by police, the legal system and finances) currently dominates the left-hand state (the feminine side of the state, e.g. represented by social and health care) in the Danish health care sector. This entails a reduced focus on dignity, ethics, life quality and democratic involvement and an increased focus on cost-benefit analysis, impact measurement, evidence-based practices and employability. Such ideas expectedly challenge an intervention form such as the youth mentor service described above because it is difficult to price (i.e. challenges calculating the many individual factors, e.g. the life situation, resources, illness expressions, and the potential positive effects of such an intervention on patients and their long-term life aspects as well as the many other people involved/affected) compared to interventions on individual physical bodies, which are easier to measure (Høgsgaard, 2018).

Hereby, it could be claimed that the welfare state takes care of people’s physical lives, but an individual’s social life is largely considered an issue for the individual family to handle. While some families are able to compensate for the altered social life situation of an injured member, others are alone with very few people surrounding them except for professionals. When the numbers of professionals and the time available to these families are reduced due to pressure on the welfare state (Pedersen, 2011), this might lead to inequalities, e.g. expressed/reflected as social isolation.

8.3. FUTURE POSSIBLE RESEARCH PATHS

This thesis has focused on the linkage between social class relations and inequality. Reduced attention has therefore been given to age, gender, racial divides and other life aspects that also could be of relevance. In the following subsections, I highlight several potential research paths that could continue using the same empirical material currently available.

8.3.1. A YOUTH PERSPECTIVE

Young adults have been the empirical centre of rotation of this thesis. Belonging to a young age group has been a criterion of inclusion, entailing that the relatives were primarily parents and siblings rather than spouses and children. This criterion also means that residential institutions with specialized competences for this target group have been provided to the young adults, creating challenges in their social lives. These factors have been mentioned in this thesis, but the focus on young adults could advantageously be further developed in future studies to understand how being in a youth life phase might impact inequality when an ABI is acquired. In the following paragraphs, I include several remarks on possible future research avenues.

The youth life phase includes the transition to adulthood, including moving away from home and living a life with increased independence. Research studies have shown that the managing of these milestones varies among young people and depends on factors such as resources and the role played by parents (Sørensen et al., 2020). People living with a disability experience that the parental care and assistance provided to them as children extend into adolescence and adult life (Jespersen et al., 2019). I expect that an ABI affects young people’s detachment process, the detachment process between young people and parents, since it is known that this kind of illness changes family roles (Gan et al., 2006; Kratz et al., 2017; Sander et al., 2002). Furthermore, the parents of chronically ill adolescents are put in situations of cognitive dissonance, hence are in the risk of becoming lost in the transition of roles as they are dismissed from the medical responsibility over their child but at the same time they still feel morally responsible for their well-being (Gabarro, Personal communication, 4th-6th of March 2021)[29].

Young life in contemporary Danish society is characterized by new types of exposures/marginalization, reflected in a failure to thrive, an explosion in psychiatric diagnoses, etc. (Görlich et al., 2019). These issues also cause more young adults to fall out of the educational system and job market, reflected as an increased polarization among the young adults (Görlich et al., 2019). A Danish study on young ABI patients (19-30 years of age) showed that this diagnosis lowered the stable labour market attachment of patients compared to a control group, and no significant improvements were seen after 2-5 years (Tibæk et al., 2019). This picture only seems to be reinforced by the severity of the ABI, as another Danish study indicates that people with sABIs have low levels of connection to the Danish labour market and are instead on public welfare (Odgaard, 2016). This suggests that an ABI might decrease life chances in a society where many young people already struggle to fit in. However, I expect this study to contribute new insights that are convertible to youth research; these insights offer a perspective of youth vulnerability caused by visible and invisible injuries that reinforce challenges and make it more difficult for young people to navigate life.

8.3.2. AN EXPLORATION OF SOCIAL NETWORK SUPPORT

In paper 2, I construct the families' personal communities in order to demonstrate structural characteristics and dynamics and thereafter combine them with their functions. Social capital was used as an analytical tool to approach inequality. However, in studying inequalities from a broader life perspective with themes of burden, including loneliness and social isolation, it would have been interesting to follow these social network dynamics of the whole family for a longer period of time (for example, incorporating my data 1½ years after hospitalization, which, due to time limitations, I have not included as data for analytical unfolding in this thesis). Hereby, reciprocity in social ties could have been unfolded in order to study how it is influenced by illness.

In addition, a specification of social relations combined with various types of support would increase our understanding of the support needs of relatives being caregivers. Negative social capital, as addressed when presenting paper 4 in this thesis, could also be included in such a study for a more nuanced and balanced picture of social network support and lack thereof. This network of the relatives is crucial to consider in order to respond to the distress the closest relatives (as well as the injured) experience. Inspiration could be found in Ketcher and Reblin (2019), who were the first to use a social network inspired methodology to study the actual compositions of social

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[29] Presentation at the international conference "Chronic living - quality, vitality and health in the 21st century" 4th-6th of March 2021

networks of the caregivers of patients with brain tumours (Ketcher & Reblin, 2019). This study distinguishes various types of support from a single time pick and visualizes these using social network mapping. However, such studies do not capture the dynamics of these social networks over time, which, as I argue, there is a need for; a comparison between the networks of different families might not make sense since family members have different support needs. Hereby, this study design could contribute a longitudinal perspective by following the same families for a longer period of time. Such a specification would enable us to prioritize the resources of the Danish welfare state and channel them to those who need it the most.

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APPENDICES

A. Technicalities on literature search

B. Consent and written information to participants

C. Observation guide

D. Interview guides

E. Surveys

Paper 1

Paper 2

Paper 3

Paper 4

Note: Paper 3 and paper 4 are not included in the official printed version due to the process of submission to journals.

Appendix A. Technicalities on literature search

In order to create an overview of related studies, I conducted literature searches for each of the papers and an overall and summative literature search for the whole thesis on inequality, NR and ABI. I delimited this search to NR (instead of including other illness/diseases or studying inequality from a broader perspective) since I consider this a unique area because of its complexity and encompassing character. Hereby, similar studies were mapped and the knowledge gap was localized. To give the reader an idea of how this literature search took place, I explain the steps taken in overall terms. I began with a simple search to gain an overview using the words 'Rehabilitation Brain injury Inequality' in Google Scholar, whereby I looked through the first seven pages of results since this database lists the results according to relevance. This search was followed by searches in the Ebscohost (inkl. Cinahl), Scopus (also covering medical results) and Social Science Premium databases in order to conduct a broad search of both social science and health-related research. The initial search words were expanded with related terms (including MEsH-words – se the table below) and used in the search process. Hereby, the prevalent manner of studying and considering inequality in NR was identified.

After practical experiences with NR, I realized that 'relatives' seemed to play a crucial role in the study of inequality. However, the relevant results for the combination of relatives, inequality, ABI and NR in the literature were limited. Instead, I searched for literature concerning relatives and NR and hereafter (in the section 'Encircling my research object…') related this to an inequality perspective.

My screening criteria included a prioritizing of Western studies with a certain transferability to a welfare state context (in a broad sense); a reference to social science theory; and literature from this millennium (with a prioritizing of studies within the past 10-15 years) since I expected changes in societies and development in the relatively new area (cf paper 1) of NR.

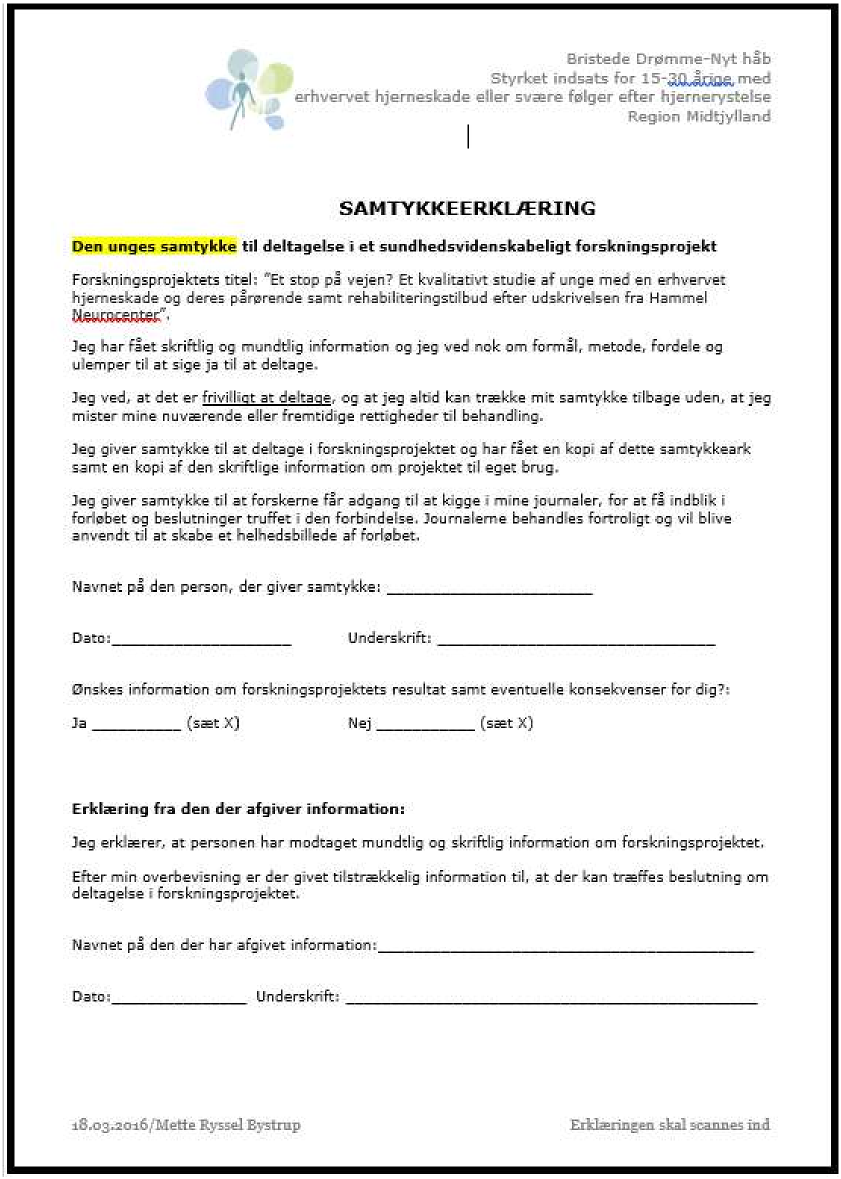
The included literature and research also contained presentations at conferences, research networks or PhD courses and contributed to the shaping of this thesis.

Block 1 – Rehabilitation	**Block 2 – Brain Injury**	**Block 3 – Inequality**	**Block 4 - Relatives**	**Block 5 – Engagement**	**Block 6 - Sociology**
“rehabilitation trajector*” OR “rehabilitation process*” OR Rehabilitation OR Rehabilitation program OR illness* OR Treatment* OR Service* OR “Care provision”	Brain injur* OR ABI OR TBI OR Stroke	Inequalit* OR Inequit* OR Equal OR unequal OR disparit*	Relative OR ”social relation*” OR caregiver* OR provider OR ”next of kin*” OR “social network” OR “significant other” OR provider OR famil* OR spous* OR sibling OR “carer” OR “social network”	“relative involv*” OR “relative inclusion” OR “relative engag*” OR “caregiver involve*” OR “caregiver inclusion” OR “caregiver engag*OR “family involve*” OR “family inclusion” OR “family engag*” OR Participat* OR empower* OR participat* OR activati* OR engag*	Sociol* OR Social science

Table 7: *Search words used in different combination and in different databases to make the literature review*

Appendix B. Written information to participants and consent

CONSENT YOUNG ADULT



Bristede Drømme-Nyt håb
Styrket indsats for 15-30 årige med
erhvervet hjerneskade eller svære følger efter hjernerystelse
Region Midtjylland

SAMTYKKEERKLÆRING

Den unges samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Forskningsprojektets titel: "Et stop på vejen? Et kvalitativt studie af unge med en erhvervet hjerneskade og deres pårørende samt rehabiliteringstilbud efter udskrivelsen fra Hammel Neurocenter".

Jeg har fået skriftlig og mundtlig information og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

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

Jeg giver samtykke til at deltage i forskningsprojektet og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Jeg giver samtykke til at forskerne får adgang til at kigge i mine journaler, for at få indblik i forløbet og beslutninger truffet i den forbindelse. Journalerne behandles fortroligt og vil blive anvendt til at skabe et helhedsbillede af forløbet.

Navnet på den person, der giver samtykke: ________________________

Dato:_____________________ Underskrift: ________________________________

Ønskes information om forskningsprojektets resultat samt eventuelle konsekvenser for dig?:

Ja __________ (sæt X) Nej ___________ (sæt X)

Erklæring fra den der afgiver information:

Jeg erklærer, at personen har modtaget mundtlig og skriftlig information om forskningsprojektet.

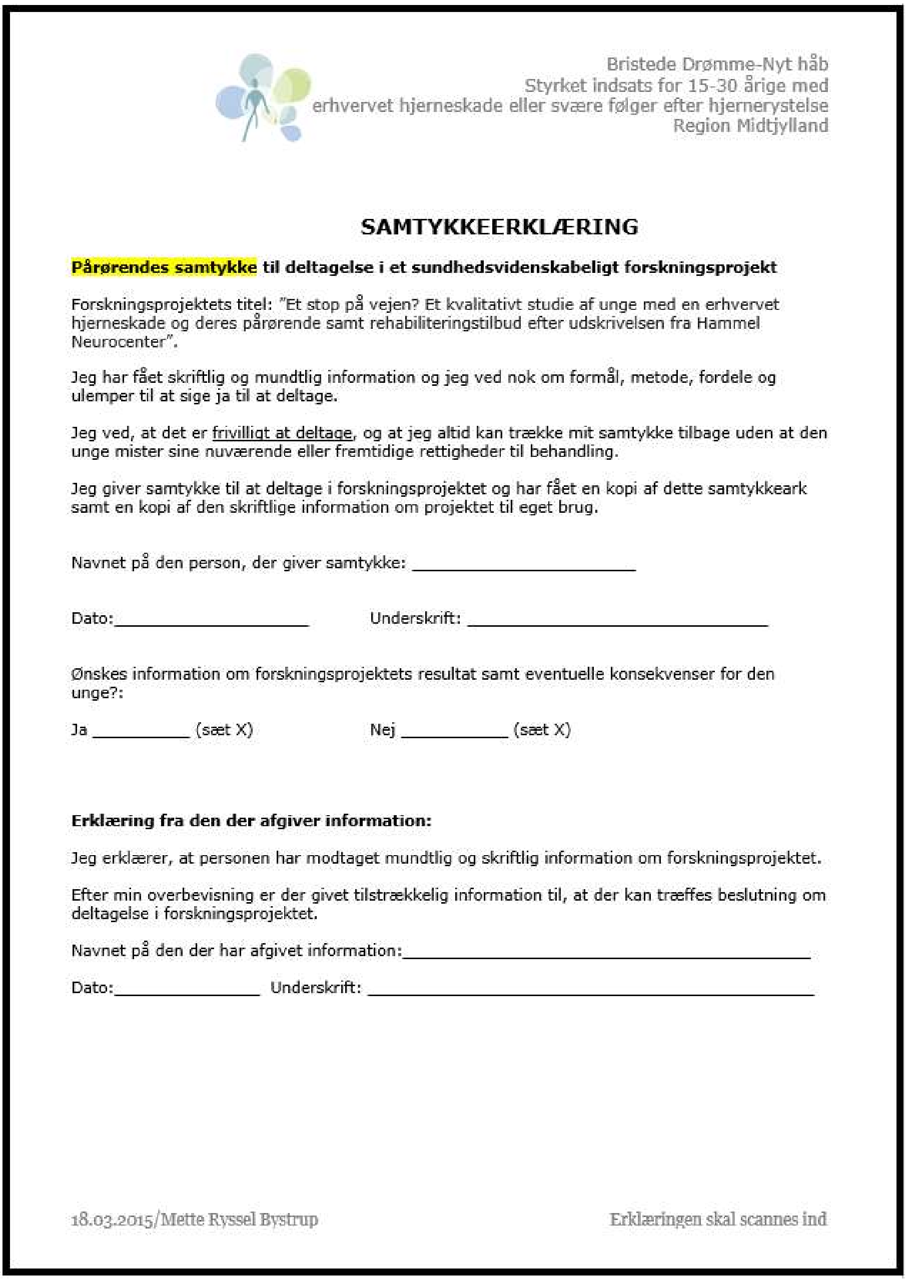
Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes beslutning om deltagelse i forskningsprojektet.

Navnet på den der har afgivet information:____

Dato:_______________ Underskrift: ____

18.03.2016/Mette Ryssel Bystrup Erklæringen skal scannes ind

CONSENT RELATIVES



Bristede Drømme-Nyt håb
Styrket indsats for 15-30 årige med
erhvervet hjerneskade eller svære følger efter hjernerystelse
Region Midtjylland

SAMTYKKEERKLÆRING

Pårørendes samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Forskningsprojektets titel: "Et stop på vejen? Et kvalitativt studie af unge med en erhvervet hjerneskade og deres pårørende samt rehabiliteringstilbud efter udskrivelsen fra Hammel Neurocenter".

Jeg har fået skriftlig og mundtlig information og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

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

Jeg giver samtykke til at deltage i forskningsprojektet og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Navnet på den person, der giver samtykke: ______________________

Dato:____________________ Underskrift: ______________________________

Ønskes information om forskningsprojektets resultat samt eventuelle konsekvenser for den unge?:

Ja __________ (sæt X) Nej ___________ (sæt X)

Erklæring fra den der afgiver information:

Jeg erklærer, at personen har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes beslutning om deltagelse i forskningsprojektet.

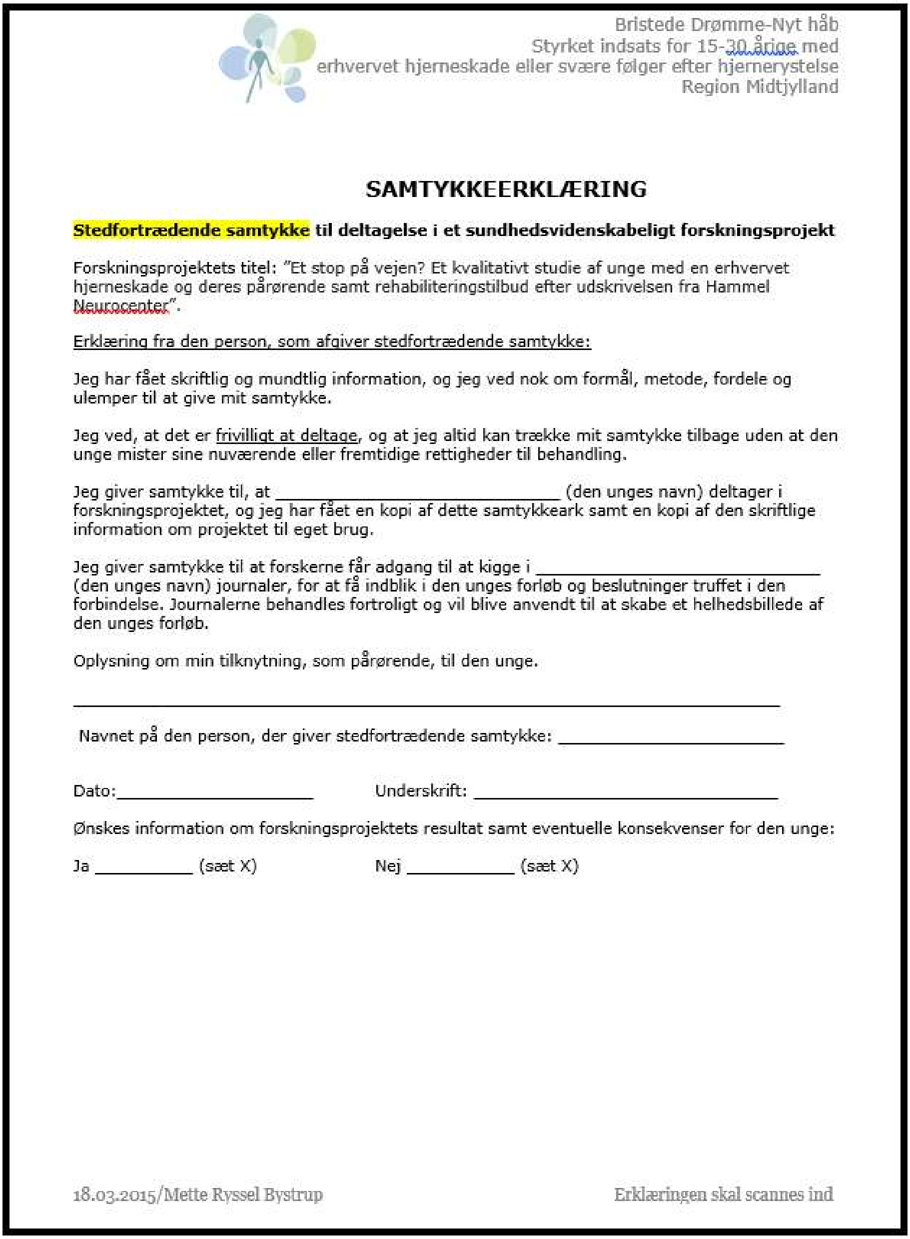
Navnet på den der har afgivet information:____

Dato:______________ Underskrift: ____

18.03.2015/Mette Ryssel Bystrup

Erklæringen skal scannes ind

SUBSTITUTE CONSENT



Bristede Drømme-Nyt håb
Styrket indsats for 15-30 årige med
erhvervet hjerneskade eller svære følger efter hjernerystelse
Region Midtjylland

SAMTYKKEERKLÆRING

Stedfortrædende samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Forskningsprojektets titel: "Et stop på vejen? Et kvalitativt studie af unge med en erhvervet hjerneskade og deres pårørende samt rehabiliteringstilbud efter udskrivelsen fra Hammel Neurocenter".

Erklæring fra den person, som afgiver stedfortrædende samtykke:

Jeg har fået skriftlig og mundtlig information, og jeg ved nok om 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 den unge mister sine nuværende eller fremtidige rettigheder til behandling.

Jeg giver samtykke til, at ______________________________ (den unges navn) deltager i forskningsprojektet, og jeg har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Jeg giver samtykke til at forskerne får adgang til at kigge i ______________________________ (den unges navn) journaler, for at få indblik i den unges forløb og beslutninger truffet i den forbindelse. Journalerne behandles fortroligt og vil blive anvendt til at skabe et helhedsbillede af den unges forløb.

Oplysning om min tilknytning, som pårørende, til den unge.

____

Navnet på den person, der giver stedfortrædende samtykke: ________________________

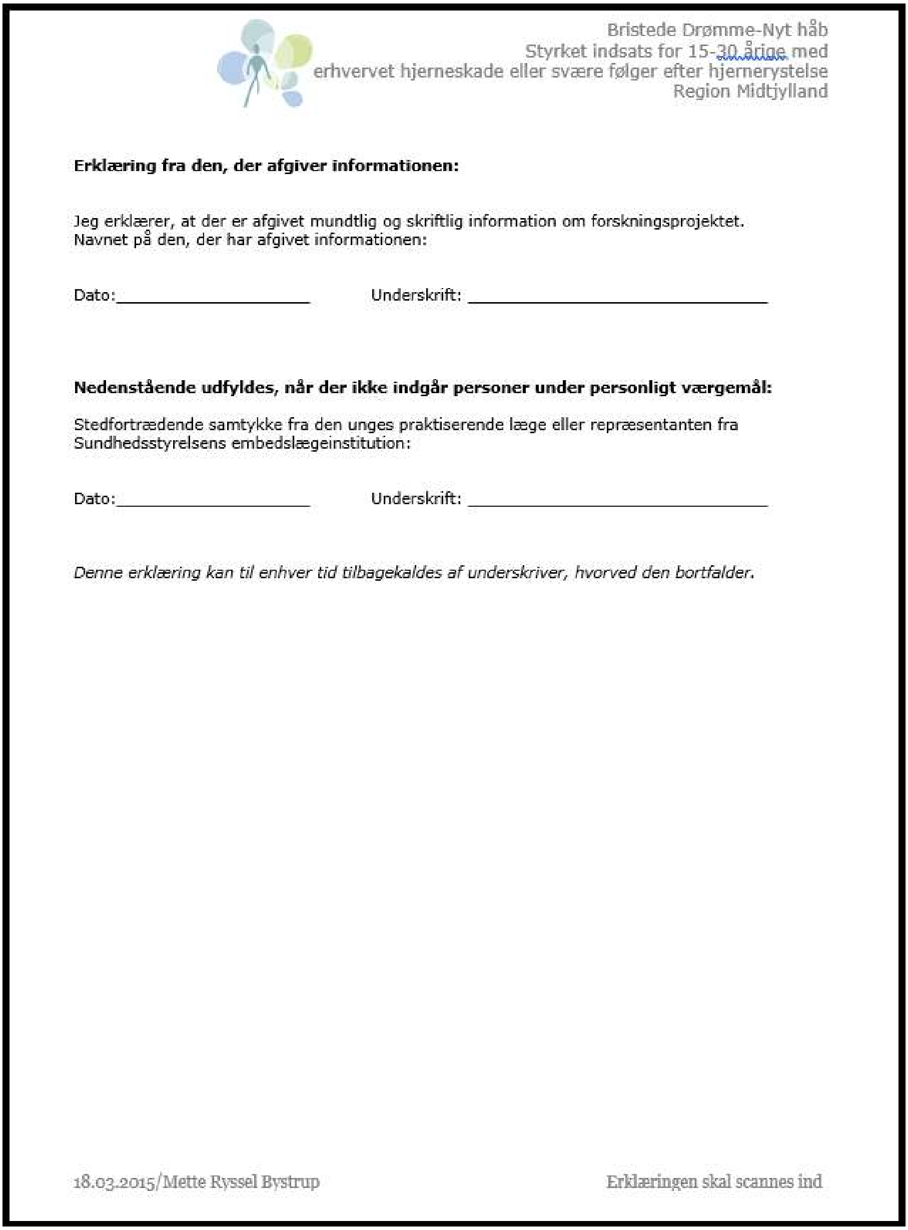
Dato: _____________________ Underskrift: ________________________________

Ønskes information om forskningsprojektets resultat samt eventuelle konsekvenser for den unge:

Ja __________ (sæt X) Nej ___________ (sæt X)

18.03.2015/Mette Ryssel Bystrup

Erklæringen skal scannes ind



Bristede Drømme-Nyt håb
Styrket indsats for 15-30 årige med
erhvervet hjerneskade eller svære følger efter hjernerystelse
Region Midtjylland

Erklæring fra den, der afgiver informationen:

Jeg erklærer, at der er afgivet mundtlig og skriftlig information om forskningsprojektet.
Navnet på den, der har afgivet informationen:

Dato:____________________ Underskrift: ______________________________

Nedenstående udfyldes, når der ikke indgår personer under personligt værgemål:

Stedfortrædende samtykke fra den unges praktiserende læge eller repræsentanten fra Sundhedsstyrelsens embedslægeinstitution:

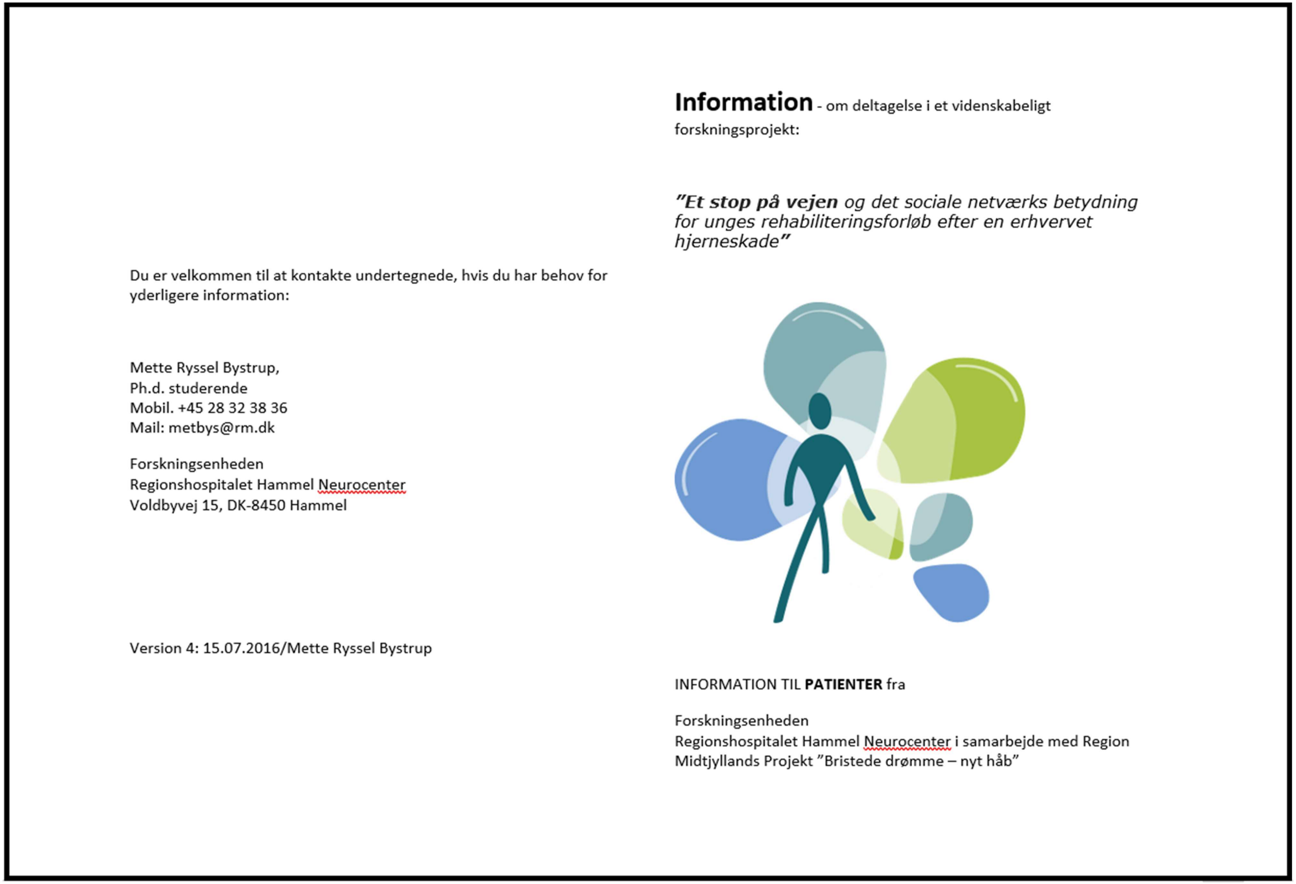
Dato:____________________ Underskrift: ______________________________

Denne erklæring kan til enhver tid tilbagekaldes af underskriver, hvorved den bortfalder.

18.03.2015/Mette Ryssel Bystrup

Erklæringen skal scannes ind

INFORMATION FOR YOUNG ADULTS



Du er velkommen til at kontakte undertegnede, hvis du har behov for yderligere information:

Mette Ryssel Bystrup,
Ph.d. studerende
Mobil. +45 28 32 38 36
Mail: metbys@rm.dk

Forskningsenheden
Regionshospitalet Hammel Neurocenter
Voldbyvej 15, DK-8450 Hammel

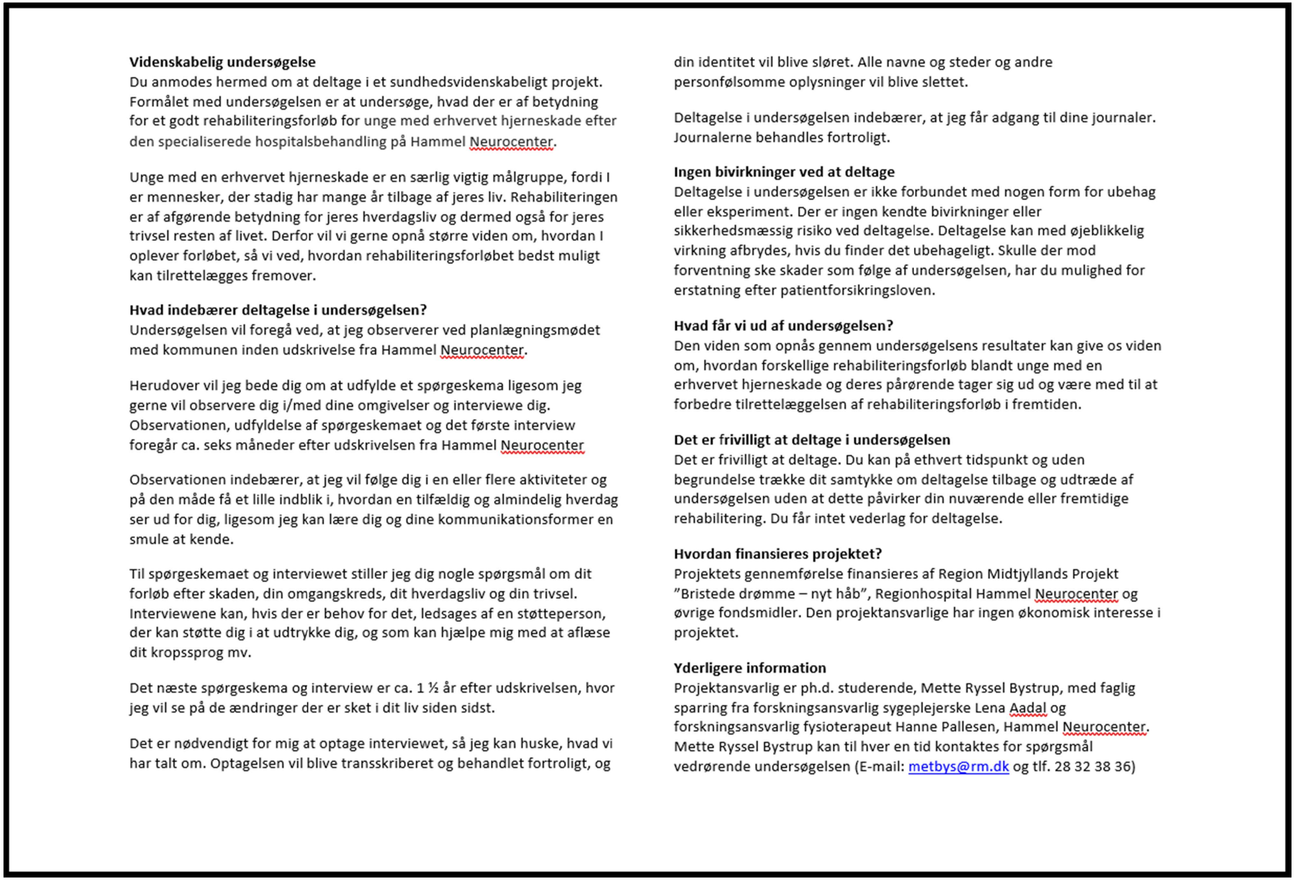
Version 4: 15.07.2016/Mette Ryssel Bystrup

Information - om deltagelse i et videnskabeligt forskningsprojekt:

”Et stop på vejen *og det sociale netværks betydning for unges rehabiliteringsforløb efter en erhvervet hjerneskade”*

INFORMATION TIL **PATIENTER** fra

Forskningsenheden
Regionshospitalet Hammel Neurocenter i samarbejde med Region Midtjyllands Projekt ”Bristede drømme – nyt håb”



Videnskabelig undersøgelse

Du anmodes hermed om at deltage i et sundhedsvidenskabeligt projekt. Formålet med undersøgelsen er at undersøge, hvad der er af betydning for et godt rehabiliteringsforløb for unge med erhvervet hjerneskade efter den specialiserede hospitalsbehandling på Hammel Neurocenter.

Unge med en erhvervet hjerneskade er en særlig vigtig målgruppe, fordi I er mennesker, der stadig har mange år tilbage af jeres liv. Rehabiliteringen er af afgørende betydning for jeres hverdagsliv og dermed også for jeres trivsel resten af livet. Derfor vil vi gerne opnå større viden om, hvordan I oplever forløbet, så vi ved, hvordan rehabiliteringsforløbet bedst muligt kan tilrettelægges fremover.

Hvad indebærer deltagelse i undersøgelsen?

Undersøgelsen vil foregå ved, at jeg observerer ved planlægningsmødet med kommunen inden udskrivelse fra Hammel Neurocenter.

Herudover vil jeg bede dig om at udfylde et spørgeskema ligesom jeg gerne vil observere dig i/med dine omgivelser og interviewe dig. Observationen, udfyldelse af spørgeskemaet og det første interview foregår ca. seks måneder efter udskrivelsen fra Hammel Neurocenter

Observationen indebærer, at jeg vil følge dig i en eller flere aktiviteter og på den måde få et lille indblik i, hvordan en tilfældig og almindelig hverdag ser ud for dig, ligesom jeg kan lære dig og dine kommunikationsformer en smule at kende.

Til spørgeskemaet og interviewet stiller jeg dig nogle spørgsmål om dit forløb efter skaden, din omgangskreds, dit hverdagsliv og din trivsel. Interviewene kan, hvis der er behov for det, ledsages af en støtteperson, der kan støtte dig i at udtrykke dig, og som kan hjælpe mig med at aflæse dit kropssprog mv.

Det næste spørgeskema og interview er ca. 1 ½ år efter udskrivelsen, hvor jeg vil se på de ændringer der er sket i dit liv siden sidst.

Det er nødvendigt for mig at optage interviewet, så jeg kan huske, hvad vi har talt om. Optagelsen vil blive transskriberet og behandlet fortroligt, og din identitet vil blive sløret. Alle navne og steder og andre personfølsomme oplysninger vil blive slettet.

Deltagelse i undersøgelsen indebærer, at jeg får adgang til dine journaler. Journalerne behandles fortroligt.

Ingen bivirkninger ved at deltage

Deltagelse i undersøgelsen er ikke forbundet med nogen form for ubehag eller eksperiment. Der er ingen kendte bivirkninger eller sikkerhedsmæssig risiko ved deltagelse. Deltagelse kan med øjeblikkelig virkning afbrydes, hvis du finder det ubehageligt. Skulle der mod forventning ske skader som følge af undersøgelsen, har du mulighed for erstatning efter patientforsikringsloven.

Hvad får vi ud af undersøgelsen?

Den viden som opnås gennem undersøgelsens resultater kan give os viden om, hvordan forskellige rehabiliteringsforløb blandt unge med en erhvervet hjerneskade og deres pårørende tager sig ud og være med til at forbedre tilrettelæggelsen af rehabiliteringsforløb i fremtiden.

Det er frivilligt at deltage i undersøgelsen

Det er frivilligt at deltage. Du kan på ethvert tidspunkt og uden begrundelse trække dit samtykke om deltagelse tilbage og udtræde af undersøgelsen uden at dette påvirker din nuværende eller fremtidige rehabilitering. Du får intet vederlag for deltagelse.

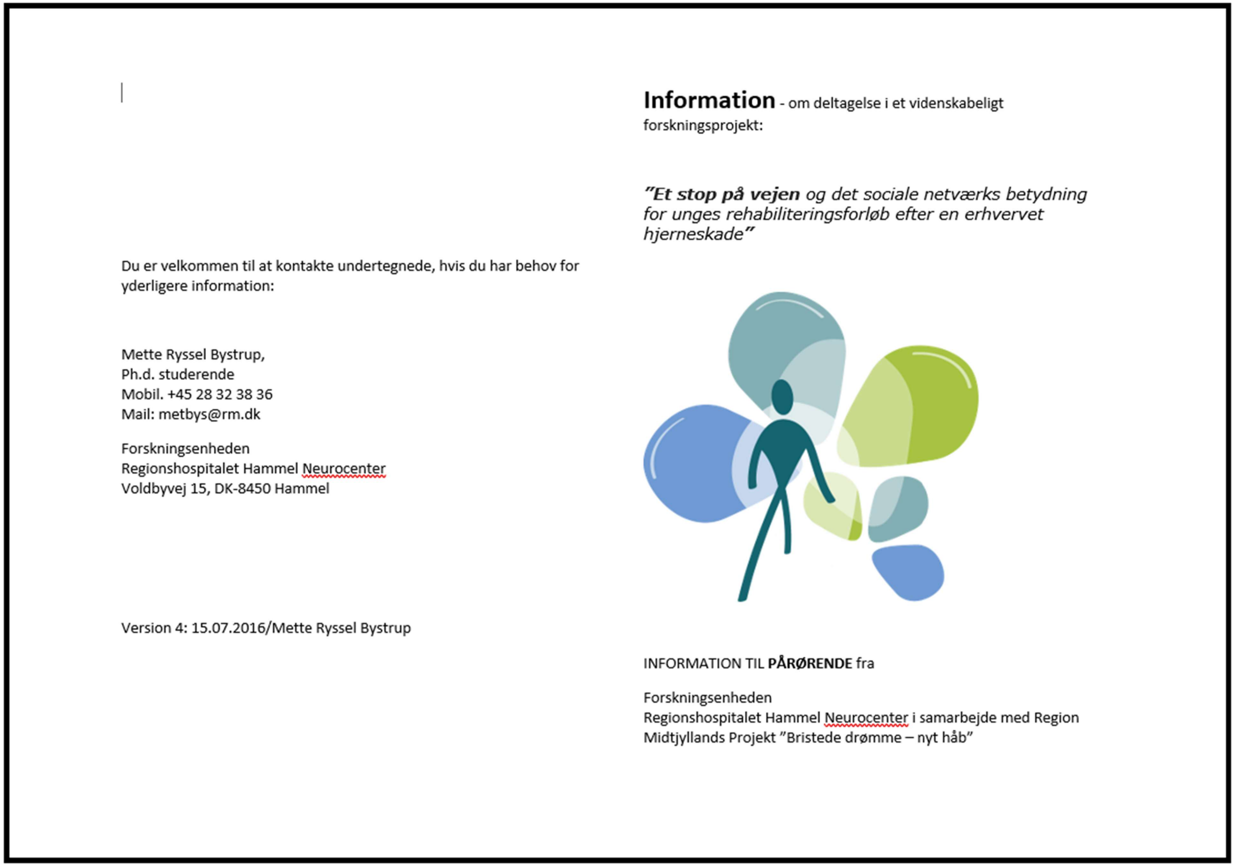
Hvordan finansieres projektet?

Projektets gennemførelse finansieres af Region Midtjyllands Projekt ”Bristede drømme – nyt håb”, Regionhospital Hammel Neurocenter og øvrige fondsmidler. Den projektansvarlige har ingen økonomisk interesse i projektet.

Yderligere information

Projektansvarlig er ph.d. studerende, Mette Ryssel Bystrup, med faglig sparring fra forskningsansvarlig sygeplejerske Lena Aadal og forskningsansvarlig fysioterapeut Hanne Pallesen, Hammel Neurocenter. Mette Ryssel Bystrup kan til hver en tid kontaktes for spørgsmål vedrørende undersøgelsen (E-mail: metbys@rm.dk og tlf. 28 32 38 36)

INFORMATION FOR RELATIVES



Du er velkommen til at kontakte undertegnede, hvis du har behov for yderligere information:

Mette Ryssel Bystrup,
Ph.d. studerende
Mobil. +45 28 32 38 36
Mail: metbys@rm.dk

Forskningsenheden
Regionshospitalet Hammel Neurocenter
Voldbyvej 15, DK-8450 Hammel

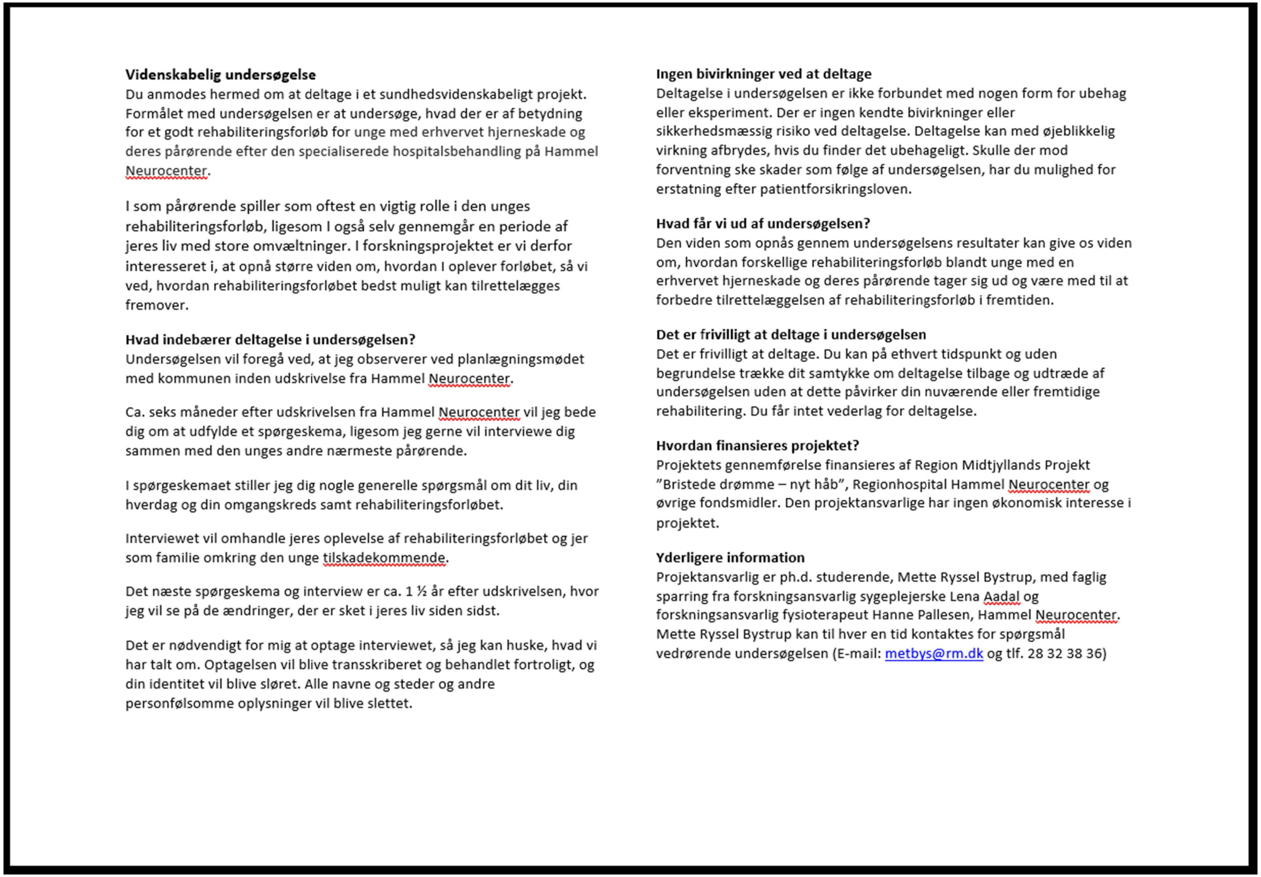
Version 4: 15.07.2016/Mette Ryssel Bystrup

Information - om deltagelse i et videnskabeligt forskningsprojekt:

***"Et stop på vejen** og det sociale netværks betydning for unges rehabiliteringsforløb efter en erhvervet hjerneskade"*

INFORMATION TIL **PÅRØRENDE** fra

Forskningsenheden
Regionshospitalet Hammel Neurocenter i samarbejde med Region Midtjyllands Projekt "Bristede drømme – nyt håb"



Videnskabelig undersøgelse
Du anmodes hermed om at deltage i et sundhedsvidenskabeligt projekt. Formålet med undersøgelsen er at undersøge, hvad der er af betydning for et godt rehabiliteringsforløb for unge med erhvervet hjerneskade og deres pårørende efter den specialiserede hospitalsbehandling på Hammel Neurocenter.

I som pårørende spiller som oftest en vigtig rolle i den unges rehabiliteringsforløb, ligesom I også selv gennemgår en periode af jeres liv med store omvæltninger. I forskningsprojektet er vi derfor interesseret i, at opnå større viden om, hvordan I oplever forløbet, så vi ved, hvordan rehabiliteringsforløbet bedst muligt kan tilrettelægges fremover.

Hvad indebærer deltagelse i undersøgelsen?
Undersøgelsen vil foregå ved, at jeg observerer ved planlægningsmødet med kommunen inden udskrivelse fra Hammel Neurocenter.

Ca. seks måneder efter udskrivelsen fra Hammel Neurocenter vil jeg bede dig om at udfylde et spørgeskema, ligesom jeg gerne vil interviewe dig sammen med den unges andre nærmeste pårørende.

I spørgeskemaet stiller jeg dig nogle generelle spørgsmål om dit liv, din hverdag og din omgangskreds samt rehabiliteringsforløbet.

Interviewet vil omhandle jeres oplevelse af rehabiliteringsforløbet og jer som familie omkring den unge tilskadekommende.

Det næste spørgeskema og interview er ca. 1 ½ år efter udskrivelsen, hvor jeg vil se på de ændringer, der er sket i jeres liv siden sidst.

Det er nødvendigt for mig at optage interviewet, så jeg kan huske, hvad vi har talt om. Optagelsen vil blive transskriberet og behandlet fortroligt, og din identitet vil blive sløret. Alle navne og steder og andre personfølsomme oplysninger vil blive slettet.

Ingen bivirkninger ved at deltage
Deltagelse i undersøgelsen er ikke forbundet med nogen form for ubehag eller eksperiment. Der er ingen kendte bivirkninger eller sikkerhedsmæssig risiko ved deltagelse. Deltagelse kan med øjeblikkelig virkning afbrydes, hvis du finder det ubehageligt. Skulle der mod forventning ske skader som følge af undersøgelsen, har du mulighed for erstatning efter patientforsikringsloven.

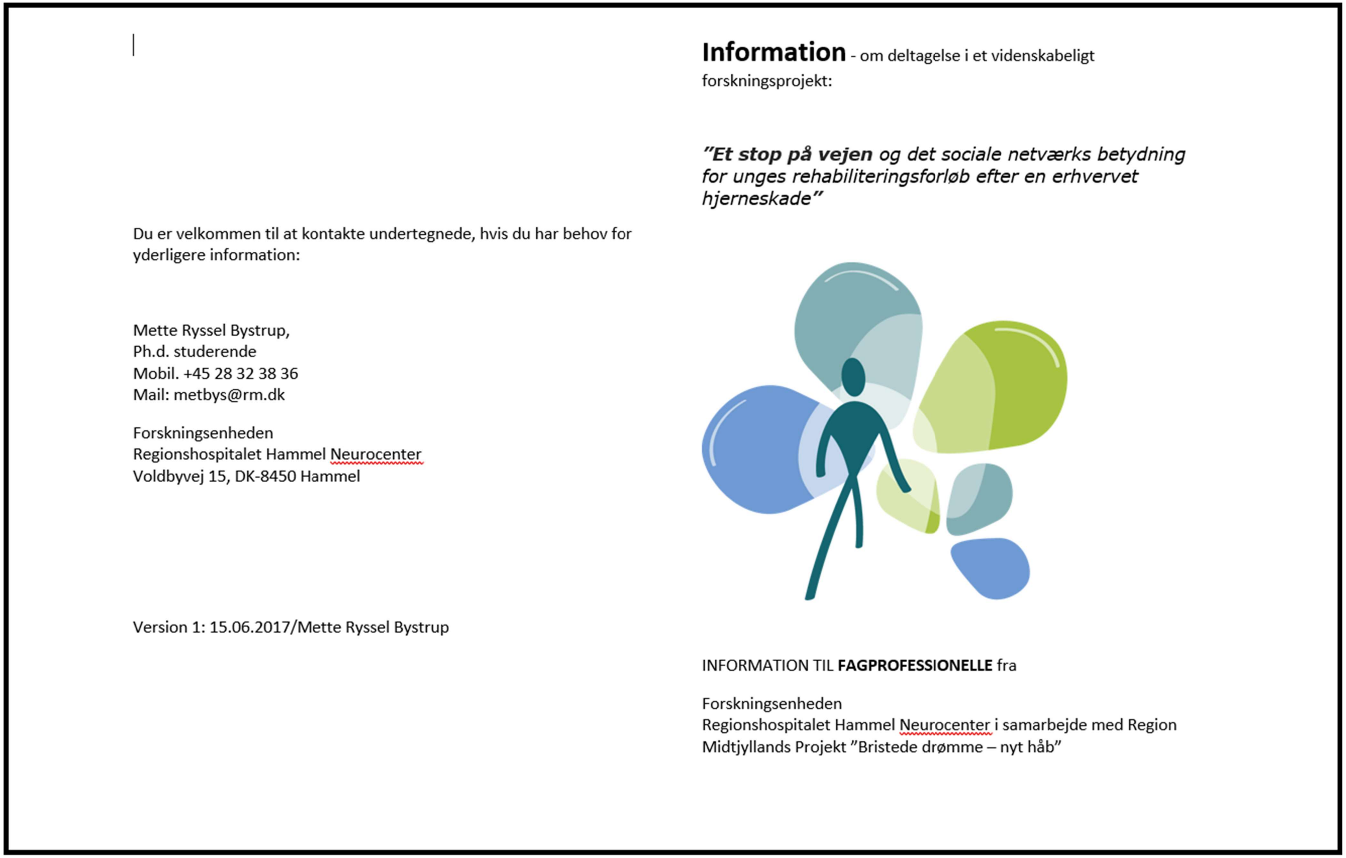
Hvad får vi ud af undersøgelsen?
Den viden som opnås gennem undersøgelsens resultater kan give os viden om, hvordan forskellige rehabiliteringsforløb blandt unge med en erhvervet hjerneskade og deres pårørende tager sig ud og være med til at forbedre tilrettelæggelsen af rehabiliteringsforløb i fremtiden.

Det er frivilligt at deltage i undersøgelsen
Det er frivilligt at deltage. Du kan på ethvert tidspunkt og uden begrundelse trække dit samtykke om deltagelse tilbage og udtræde af undersøgelsen uden at dette påvirker din nuværende eller fremtidige rehabilitering. Du får intet vederlag for deltagelse.

Hvordan finansieres projektet?
Projektets gennemførelse finansieres af Region Midtjyllands Projekt "Bristede drømme – nyt håb", Regionhospital Hammel Neurocenter og øvrige fondsmidler. Den projektansvarlige har ingen økonomisk interesse i projektet.

Yderligere information
Projektansvarlig er ph.d. studerende, Mette Ryssel Bystrup, med faglig sparring fra forskningsansvarlig sygeplejerske Lena Aadal og forskningsansvarlig fysioterapeut Hanne Pallesen, Hammel Neurocenter. Mette Ryssel Bystrup kan til hver en tid kontaktes for spørgsmål vedrørende undersøgelsen (E-mail: metbys@rm.dk og tlf. 28 32 38 36)

INFORMATION FOR PROFESSIONALS



Du er velkommen til at kontakte undertegnede, hvis du har behov for yderligere information:

Mette Ryssel Bystrup,
Ph.d. studerende
Mobil. +45 28 32 38 36
Mail: metbys@rm.dk

Forskningsenheden
Regionshospitalet Hammel Neurocenter
Voldbyvej 15, DK-8450 Hammel

Version 1: 15.06.2017/Mette Ryssel Bystrup

Information - om deltagelse i et videnskabeligt forskningsprojekt:

***"Et stop på vejen** og det sociale netværks betydning for unges rehabiliteringsforløb efter en erhvervet hjerneskade"*

INFORMATION TIL **FAGPROFESSIONELLE** fra

Forskningsenheden
Regionshospitalet Hammel Neurocenter i samarbejde med Region Midtjyllands Projekt "Bristede drømme – nyt håb"

Videnskabelig undersøgelse
Den videnskabelige undersøgelse indgår som en del af et ph.d. projekt, som forventes afsluttet ultimo 2020 med et ph.d. forsvar. I perioden indtil da, vil der løbende blive udgivet 3-5 peer-reviewed artikler på baggrund af datamaterialet.

Undersøgelsens formål
Formålet med undersøgelsen er at opnå viden om, hvordan forskellige rehabiliteringsforløb blandt unge med en erhvervet hjerneskade og deres pårørende tager sig ud, og hvad der ser ud til at være af afgørende betydning for udfaldet. Undersøgelsen har et særligt fokus på de pårørendes betydning for rehabiliteringsforløbet, fordi undersøgelser viser, at pårørende spiller en vigtig rolle for unges rehabiliteringsforløb, ligesom de også selv gennemgår en periode af deres liv med store omvæltninger.

Hvad indebærer deltagelse i undersøgelsen?
Umiddelbart inden udskrivelse fra Hammel Neurocenter
Undersøgelsen foregår ved, at jeg observerer ved det eventuelle planlægningsmøde med kommunen inden udskrivelse fra Hammel Neurocenter (primært Region Midtjylland borgere).

6 mdr. efter udskrivelse fra Hammel Neurocenter:
Interviews med henholdsvis den unge, de pårørende og fagprofessionelle

Interviewet med de fagprofessionelle vil omhandle jeres oplevelse af rehabiliteringsforløbet og samarbejdet med andre institutioner omkring forløbet (fx Hammel Neurocenter, rehabiliteringsinstitutioner, kommuner mv.) og den unge og familien.

1½ år efter udskrivelsen
Interviews med henholdsvis den unge og de pårørende, hvor der fokuseres på livsændringer siden sidst.

Databehandling
Det er nødvendigt for mig at optage interviewet, så jeg kan huske, hvad vi har talt om. Optagelsen vil blive transskriberet og behandlet fortroligt, og jeres (og institutionens) identitet vil blive anonymiseret. Alle navne og steder og andre personfølsomme oplysninger vil blive slettet umiddelbart efter behandlingen af materialet.

Ingen bivirkninger ved at deltage
Deltagelse i undersøgelsen er ikke forbundet med nogen form for ubehag eller eksperiment. Der er ingen kendte bivirkninger eller sikkerhedsmæssig risiko ved deltagelse. Deltagelse kan med øjeblikkelig virkning afbrydes, hvis du finder det ubehageligt.

Hvordan finansieres projektet?
Projektets gennemførelse finansieres af Region Midtjyllands Projekt ”Bristede drømme – nyt håb”, Regionhospital Hammel Neurocenter og øvrige fondsmidler. Den projektansvarlige har ingen økonomisk interesse i projektet.

Yderligere information
Projektansvarlig er ph.d. studerende, Mette Ryssel Bystrup, med faglig sparring fra forskningsansvarlig sygeplejerske Lena Aadal og forskningsansvarlig fysioterapeut Hanne Pallesen, Hammel Neurocenter. Mette Ryssel Bystrup kan til hver en tid kontaktes for spørgsmål vedrørende undersøgelsen (E-mail: metbys@rm.dk og tlf. 28 32 38 36)

Appendix C. Observation guide

OBSERVATION GUIDE – DISCHARGE MEETING

Tema	**Fokusområder**
Deltagere	- Relation til patient? - Køn? - Antal af pårørende - Antal af sundhedsprofessionelle
Rammer	- Hvor foregår mødet? - Fysiske rammer? - Placering omkring bordet? (tilfældigt/strategisk) - Varighed af mødet? - Tidspunkt på dagen? - Forstyrrelser under mødet?
Mødets forløb og indhold	- Mødeleder? - Indledning? - Præsentation af deltagere og formål? - Varighed, tidspunkt, forstyrrelser (hvad kan afbryde?) - Initiativ, respons, går ordet på skift? - Uenigheder/misforståelser (hvordan takles det?) - Stemning (personlig, varm > < kold/affærdigende) - Definitionsretten? - Magtfordeling blandt deltagerne (fx definitionsretten, taleret og -tid, tilgodeseelse af ønsker/behov)? - Argumentation - Konsensus og diskussion/forhandlingspunkter (udtryk for ønsker/behov og spørges der til det? Kritiske spørgsmål? Stilles der krav?) - Sprogbrug (biomedicinsk, lægmand-hverdagsbegreber, administrativ)? - Kropssprog (Åbent/lukket, offensiv/defensiv, gestik, mimik) - Stemning? - Afslutning?
Observatørens rolle	- Vækker jeg opsigt? - Henvendelser (øjenkontakt) fra patient/pårørende? - Medbragte remedier? - Min placering i rummet?

Appendix D. Interview guides

INTERVIEWGUIDE ½ YEAR AFTER DISCHARGE - YOUNG ADULTS

Tema	**Spørgsmål**
Hverdagen og trivsel	• Fortæl om de ændringer der er sket i dit liv efter skaden? • Hvilken betydning har ændringerne betydet for den måde du har det? • Hvordan har du det for tiden? Ophold på XXX? • Hvad er det vigtigste for dig i dit liv lige for tiden? • Har det ændret sig efter skaden?
Udfordringer	• Nævn de 3 største udfordringer du har oplevet siden skaden? • Hvordan har du håndteret udfordringerne? • Var det også den måde du klarede udfordringer inden skaden? • Har du fået hjælp af andre til at klare udfordringerne? • Har du nogle ressourcer du kan trække på, når du står i sådan nogle situationer?
Hjælp og støtte	• Er der nogen eller noget der har haft særlig stor betydning for dig i perioden efter skaden? • Har du fået den hjælp og støtte du har haft brug for? Hvilken? • Kunne du have haft brug for anden hjælp/støtte?
Relationer	• Beskriv hvordan du har det med personalet? • Beskriv hvordan du har det med din familie (før og efter skaden)? • Hvad har skaden betydet for jeres måde og være familie på? • Beskriv hvordan du har det med dine venner (før og efter skaden)? • Hvad gør du, hvis du er ked af det? (evt. Hvem)? • Deler du det med nogen, hvis du er glad? • Hvis der er noget du gerne vil, oplever du så, at der er nogen der lytter til dig? Hvem? (Hvad kunne det være)

	• Hvis der er noget du ikke vil, oplever du så, at der er nogen der lytter til dig? Hvem? (Hvad kunne det være)?
Fremtiden	• Hvordan ser dit liv ud om ½ år? Om 5 år? Udfordringer? • Er der forskel på hvordan du tror det kommer til at se ud og hvordan du håber det ser ud? • Hvad skal der til for at det kommer til at se sådan ud?
Gode råd	• Er der noget du synes, at andre unge, der kommer til skade med hovedet skal vide?
Afslutning	• Er der noget jeg ikke har tænkt på at spørge dig om, som du har lyst til at tilføje? • Må jeg kontakte dig, hvis jeg har yderligere spørgsmål? Hvordan?

INTERVIEWGUIDE 1½ YEAR AFTER DISCHARGE - YOUNG ADULTS

Tema	**Spørgsmål**
Siden sidst	• Opfølgning på, hvad der blev fortalt sidst
Hverdagen og trivsel	• Hvordan ser dit liv ud siden vi sås sidst? • Fortæl om de ændringer skaden har betydet for dit liv (socialt, arbejdsmæssigt, økonomisk, venner, fritid) • Hvilken betydning har ændringerne betydet for din trivsel? • Hvordan har du det for tiden? • Hvad er det vigtigste for dig i dit liv lige for tiden? • Har det ændret sig efter skaden?
Udfordringer	• Nævn de 3 største udfordringer du har oplevet siden skaden? • Hvordan har du håndteret udfordringerne? • Var det også den måde du klarede udfordringer inden skaden? • Har du nogen eller noget du kan trække på, når du står i sådan nogle situationer? Hvem? Hvad?
Hjælp og støtte	• Er der nogen eller noget der har haft særlig stor betydning for dig siden vi sås sidst? • Har du fået den hjælp og støtte du har haft brug for? Hvilken? • Kunne du have haft brug for anden hjælp/støtte?
Relationer	• Har jeres måde at være familie på ændret sig siden vi sås sidst? • Hvad har skaden betydet for jeres måde og være familie på? • Beskriv hvordan du har det med dine venner (før og efter skaden)? • Hvad gør du, hvis du er ked af det? (evt. Hvem)? • Deler du det med nogen, hvis du er glad?
Fremtiden	• Hvordan ser dit liv ud om ½ år? Om 5 år? Udfordringer? • Er der forskel på hvordan du tror det kommer til at se ud og hvordan du håber det ser ud?

	• Hvad skal der til for at det kommer til at se sådan ud?
Gode råd	• Er der noget du synes, at andre unge, der kommer til skade med hovedet skal vide?
Afslutning	• Er der noget jeg ikke har tænkt på at spørge dig om, som du har lyst til at tilføje? • Må jeg kontakte dig, hvis jeg har yderligere spørgsmål? Hvordan?

INTERVIEWGUIDE ½ YEAR AFTER DISCHARGE – RELATIVES

Tema	**Spørgsmål**
Livsændringer	• Fortæl om de ændringer skaden har betydet for jeres liv? (socialt, arbejdsmæssigt, økonomisk, fritidsinteresser) • Hvilken betydning har ændringerne betydet for jeres trivsel?
Udfordringer	• Nævn de 3 største udfordringer I har oplevet ifbm. rehabiliteringsforløbet? • Hvordan tackler I de udfordringer I har mødt siden ulykken? • Var det også den måde I taklede udfordringer på inden skaden? • Har I fået hjælp af andre til at klare udfordringerne? Hvem? Hvordan?
Hjælp/støtte	• Er der nogen eller noget der har haft særlig afgørende betydning for jer i perioden efter hjerneskaden? • Har der efter skaden været nogle personer eller tiltag, som har hjulpet/støttet jer? • Kunne I have haft brug for anden hjælp/støtte? Hvem? Hvordan? • Hvordan forholder I jer til de fagpersoner, der er og har været omkring XXX i rehabiliteringsforløbet?
Familieændringer og -ressourcer	• Hvad har forløbet betydet for jeres måde at være familie på? Rollefordeling? • Oplever I, at I som familie har nogle ressourcer I kan bruge ifbm. det her forløb I gennemgår? • I hvilke situationer oplever I, at I kommer til kort? Hjælp og støtte I har behov for?
Fremtiden	• Hvad tænker I om XXX's hverdag, når forløbet på (fx institution) stopper • Hvad tænker I om jeres hverdag, når forløbet på (fx institution) stopper • Hvordan ser jeres liv ud om ½ år? Om 5 år? Udfordringer?

	• Er der forskel på, hvordan I *tror* det ser ud, og hvordan I *håber* det ser ud? • Hvad skal der til for at det kommer til at se sådan ud?
Råd/efterrefleksioner	• Er der noget I synes, at andre familier til unge, der erhverver en hjerneskade skal vide? • Er der noget I synes fagprofessionelle der arbejder med unge der erhverver en hjerneskade skal vide? • Er der noget jeg ikke har tænkt på at spørge jer om, som I har lyst til at tilføje?

INTERVIEWGUIDE 1½ YEAR AFTER DISCHARGE - RELATIVES

Tema	**Spørgsmål**
Siden sidst	• Opfølgning på, hvad der blev fortalt sidst
Livsændringer	• Fortæl om de ændringer skaden har betydet for jeres liv? (socialt, arbejdsmæssigt, økonomisk, fritidsinteresser) • Hvilken betydning har ændringerne betydet for jeres trivsel?
Udfordringer	• Nævn de 3 største udfordringer I har oplevet ifbm. rehabiliteringsforløbet? • Hvordan tackler I de udfordringer I møder? • Var det også den måde I taklede udfordringer på inden skaden? • Har I fået hjælp af andre til at klare udfordringerne? Hvem? Hvordan?
Hjælp/støtte	• Er der nogen eller noget der har haft særlig afgørende betydning for jer i forløbet? • Har der efter skaden været nogle personer eller tiltag, som har hjulpet/støttet jer? • Kunne I have haft brug for anden hjælp/støtte? Hvem? Hvordan? • Hvordan forholder I jer til de fagpersoner, der er og har været omkring XXX i rehabiliteringsforløbet?
Familieændringer og -ressourcer	• Hvad har forløbet betydet for jeres måde at være familie på? • Oplever I, at I som familie har nogle ressourcer I kan bruge ifbm. det her forløb I gennemgår? • I hvilke situationer oplever I, at I kommer til kort? Hjælp og støtte I har behov for?
Fremtiden	• Hvordan ser jeres liv ud om ½ år? Om 5 år? Udfordringer? • Er der forskel på, hvordan I *tror* det ser ud, og hvordan I *håber* det ser ud? • Hvad skal der til for at det kommer til at se sådan ud?

Råd/ efterrefleksioner	• Hvis det her forløb skulle gøres om, hvordan skulle det så have været? • Er der noget I synes, at andre familier til unge, der erhverver en hjerneskade skal vide? • Er der noget I synes fagprofessionelle der arbejder med unge der erhverver en hjerneskade skal vide? • Er der noget jeg ikke har tænkt på at spørge jer om, som I har lyst til at tilføje?

INTERVIEWGUIDE ½ YEAR AFTER DISCHARGE PROFESSIONALS

Tema	**Spørgsmål**
Rehabiliterings-forløbet	• Beskriv hvordan I samlet set oplever den unges rehabiliteringsforløb indtil videre? (sammenhæng, koordination, samarbejde mellem sygehuse, rehab. Institutioner, kommuner mv.) • Beskriv jeres oplevelse af beslutningsprocesser forbundet med den unges forløb?
Rehabilitering af den unge	• Fortæl hvad I opfatter som jeres vigtigste opgaver ifht. den unge? Hvorfor er det vigtigt? • Beskriv den måde I sammen og hver især arbejder med den unge? Giv eksempler • Beskriv hvad eller hvem der definerer/sætter rammerne for jeres arbejde ifht. den unge og de pårørende?
De pårørende	• Fortæl om den måde I forholder jer til den unges pårørende i jeres arbejde? Giv eksempler? • Hvad lægger I vægt på i arbejdet med de pårørende? • Hvor oplever I at familien har deres ressourcer i den her sammenhæng? • Er der nogle områder, hvor I oplever, at den unges nære netværk kommer til kort ifht. at kunne håndtere den situation de står i? Hvordan forholder I jer til det?
Fremtiden	• Fortæl hvad I tænker om den unges fremtid? • Fortæl hvad I tænker om de pårørendes fremtid? • Hvad opfatter I som jeres vigtigste indsatsområder i fremtiden? • Forslag til ændringer til lignende forløb eller andre fagprofessionelle der arbejder med unge i lignende situation?
Debriefing	• Er der noget I gerne vil tilføje til interviewet, som vi ikke er kommet omkring? • Må jeg kontakte jer, hvis der er noget vi mangler at få uddybet? • Hvordan oplevede I det at blive interviewet?

Appendix E. Surveys

SURVEY ½ YEAR AFTER DISCHARGE – YOUNG ADULTS

Kære ___________________________

Tak fordi du deltager i undersøgelsen *” Et stop på vejen og det sociale netværks betydning for unges rehabiliteringsforløb og livssituation efter en erhvervet hjerneskade”*.

Som en del af undersøgelsen vil vi bede dig om at svare på nedenstående spørgeskema.

Spørgsmålene omhandler blandt andet dine relationer, hvor du vil blive bedt om at oplyse fulde navne. Navnene vil kun blive brugt i analysesammenhæng og vil herefter blive slettet. Alle oplysninger vil blive behandlet fortroligt og data (herunder alle navne) vil blive slettet, når de er færdiganalyseret.

For yderligere oplysninger om undersøgelsen stiller Mette Ryssel Bystrup sig gerne til rådighed samt henvises til den udleverede informationsfolder.

Mange tak for besvarelsen!

Tak fordi du deltager i undersøgelsen ”Et stop på vejen?” under projekt ”Bristede drømme – nyt håb”.

Dato: __________________________

Dine sociale relationer

1. **Hvem betød mest for dig inden du kom tilskade (og hvor ofte havde du kontakt med dem)?** *(Nævn fulde navn og relation (fx. søster, kollega eller lignende) til den du havde den tætteste relation til som nr. 1, den du har den næsttætteste relation til som nr. 2 osv. Du må nævne så mange, som du vil)*

	Dagligt	**Ugentligt**	**Månedligt**	**Sjældnere end hver måned**	**Andet**	**Ved ikke**
1. ____________________	☐	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐	☐
10. ___________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

2. Hvem betyder mest for dig nu (og hvor ofte har du kontakt med dem)??

	Dagligt	Ugentligt	Månedligt	Sjældnere end hver måned	Andet	Ved ikke
1. ____________________	☐	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐	☐
10. ___________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

3. Hvem (angiv med navn) hjælper dig med…?

	Udfyldelse af papirer til kommunen og lignende	Indkøb af tøj/ting du har brug for	Følelsesmæssige udfordringer	Kommunikationen med fagpersoner i rehabiliteringsforløbet?	Økonomiske forhold
1. ____________________	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐
10.____________________	☐	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

Rehabiliteringsforløbet

4. **Har du forsikringer (fx kritisk sygdom), der kommer dig til gode under dit sygdomsforløb?**

☐ Ja

☐ Nej

☐ Ved ikke

Hvis ja, hvilke?

____

____

5. **Havde du erfaringer med det danske social- og sundhedsvæsen inden skaden?**

☐ Slet ikke

☐ I lav grad

☐ I nogen grad

☐ I høj grad

☐ I meget høj grad

Hvis ja, hvilke?

____

Afslutning

Har du yderligere bemærkninger til nogle af spørgsmålene i spørgeskemaet?

____

____

Tak for besvarelsen af spørgeskemaet!

SURVEY 1½ YEAR AFTER DISCHARGE – YOUNG ADULTS

Kære ___________________________

Tak fordi du deltager i undersøgelsen *" Et stop på vejen og det sociale netværks betydning for unges rehabiliteringsforløb og livssituation efter en erhvervet hjerneskade"*.

Som en del af undersøgelsen vil vi bede dig om at svare på nedenstående spørgeskema.

Spørgsmålene omhandler blandt andet dine relationer, hvor du vil blive bedt om at oplyse fulde navne. Navnene vil kun blive brugt i analysesammenhæng og vil herefter blive slettet. Alle oplysninger vil blive behandlet fortroligt og data (herunder alle navne) vil blive slettet, når de er færdiganalyseret.

For yderligere oplysninger om undersøgelsen stiller Mette Ryssel Bystrup sig gerne til rådighed samt henvises til den udleverede informationsfolder.

Mange tak for besvarelsen!

Dato: __________________________

Dine sociale relationer

1. **Hvilke personer (angiv med fulde navn) har du den tætteste relation til i dag, og hvor ofte har du kontakt med dem** *Nævn fulde navn og relation (fx. søster, kollega eller lignende) til den du havde den tætteste relation til som nr. 1, den du har den næsttætteste relation til som nr. 2 osv. Du må nævne så mange, som du vil)*?

	Dagligt	**Ugentligt**	**Månedligt**	**Sjældnere end hver måned**	**Andet**	**Ved ikke**
1. ____________________	☐	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐	☐
10. ___________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

2. Hvem (angiv med navn) hjælper dig med…?

	Udfyldelse af papirer til kommunen og lignende	Indkøb af tøj/ting du har brug for	Følelsesmæssige udfordringer	Kommunikationen med fagpersoner i rehabiliteringsforløbet?	Økonomiske forhold
1. ____________________	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐
10.____________________	☐	☐	☐	☐	☐

Andet (hvem og hvad)?

____

Afslutning

Har du yderligere bemærkninger til nogle af spørgsmålene i spørgeskemaet?

____

____

Tak for besvarelsen af spørgeskemaet!

SURVEY ½ YEAR AFTER DISCHARGE – RELATIVES

Kære pårørende til den unge

Tak fordi du deltager i undersøgelsen *" Et stop på vejen og det sociale netværks betydning for unges rehabiliteringsforløb og livssituation efter en erhvervet hjerneskade"*.

Som en del af undersøgelsen vil vi bede dig om at svare på nedenstående spørgeskema.
Spørgsmålene omhandler blandt andet dine relationer, hvor du vil blive bedt om at oplyse fulde navne. Navnene vil kun blive brugt i analysesammenhæng og vil herefter blive slettet. Alle oplysninger vil blive behandlet fortroligt og data (herunder alle navne) vil blive slettet, når de er færdiganalyseret.

For yderligere oplysninger om undersøgelsen stiller Mette Ryssel Bystrup sig gerne til rådighed samt henvises til den udleverede informationsfolder.

Mange tak for besvarelsen!

Dato: ________________

Generelle oplysninger

1. **Relation til den unge?**
   - ☐ Forældre
   - ☐ Søskende
   - ☐ Ægtefælle eller samlever
   - ☐ Søn eller datter
   - ☐ Anden familie
   - ☐ Ven
   - ☐ Nabo
   - ☐ Kollega
   - ☐ Anden relation (skriv hvilken)? ________________
   - ☐ Ved ikke

2. **Køn**
   - ☐ Dreng / Mand
   - ☐ Pige / Kvinde

3. **Alder** ___________ år

4. **Hvad er din ægteskabelige status rent juridisk?**
   - ☐ Gift
   - ☐ Registreret partnerskab
   - ☐ Separeret
   - ☐ Skilt
   - ☐ Enke(mand)
   - ☐ Ugift
   - ☐ Ved ikke

5. Er du fast samlevende i papirløst ægteskab?

☐ Ja

☐ Nej

☐ Ved ikke

6. Hvem bor du sammen med?

☐ Bor alene *(fx som single, enke eller enkemand)*

☐ Bor sammen med nogen *(fx forældre, ægtefælle, børn, anden familie bekendte eller i bofællesskab)*

☐ Andet *(angiv hvad)*

____

☐ Ved ikke

7. Hvor mange voksne på 18 år og derover bor der i husstanden? (Skriv antal)

_________ voksne

8. Hvor mange børn på 17 år og derunder bor der i husstanden? (Skriv antal)

_________ børn

9. Hvad er din husstands samlede indkomst før skat?

☐ Under 150.000 kr

☐ 150.000 - 299.999 kr

☐ 300.000 - 499.999 kr

☐ 500.000 - 799.999 kr.

☐ 800.000 kr. eller derover

☐ Ved ikke

Uddannelse og job

10. Hvad er den længste uddannelse, du har fuldført (sæt kun ét kryds) ?

☐ Går stadig i skole
☐ 7 eller færre års skolegang
☐ 8 – 9 års skolegang
☐ 10-11 års skolegang
☐ Studenter- eller Hf-eksamen (inkl. HHX, HTX)
☐ Erhvervsfaglig uddannelse/faglært (fx kontor- eller butiksassistent, frisør, murer, lægesekretær, social- og sundhedshjælper/-assistent, landmand)
☐ Kort videregående uddannelse, 2-3 år (fx markedsøkonom, politibetjent, laborant, maskintekniker, datamatiker, multimediedesigner, økonoma, tandplejer)
☐ Mellemlang videregående uddannelse, 3-4 år (fx folkeskolelærer, socialrådgiver, bygningskonstruktør, sygeplejerske, diplomingeniør, pædagog, bachelor)
☐ Lang videregående uddannelse, mere end 4 år
☐ Ved ikke

11. Hvad var din beskæftigelse på skadestidspunktet?

☐ Under uddannelse

☐ Værnepligtig

☐ I arbejde på normale vilkår

☐ I arbejde på særlige vilkår (fx fleksjob, skånejob, løntilskud)

☐ Arbejdsløs på dagpenge eller kontanthjælp

☐ Førtidspension

☐ Sygedagpenge

☐ Anden overførselsindkomst

☐ Efterløn/Pension

☐ Andet ________________

☐ Ved ikke

12. Har din beskæftigelse ændret sig siden skadestidspunktet?

☐ Ja

☐ Nej

☐ Ved ikke

Hvis ja, hvordan?

____

____

13. Hvad er din <u>nuværende</u> stillingsbetegnelse?

____

14. Har du, eller har du haft orlov i forbindelse med den unge tilskadekomnes sygdomsforløb?

☐ Ja

☐ Nej

☐ Ved ikke

☐ Ikke relevant

Hvis ja - hvor længe?

____

15. Er du, eller har du selv været sygemeldt i forbindelse med den unge tilskadekomnes sygdomsforløb?

☐ Ja, fuldt sygemeldt

☐ Ja, delvist sygemeldt

☐ Nej

☐ Ved ikke

☐ Ikke relevant

Hvis ja - hvor længe?

____

16. I de sidste 7 dage... Hvor meget indvirkede den unge tilskadekomnes situation din arbejdsindsats på dit arbejde?

☐ Overhovedet ikke
☐ I mindre grad
☐ I nogen grad
☐ I høj grad
☐ I meget høj grad
☐ Ved ikke
☐ Ikke relevant

17. I de sidste 7 dage... Hvor meget indvirkede den unge tilskadekomnes situation dig i dine øvrige daglige aktiviteter?

☐ Overhovedet ikke
☐ I mindre grad
☐ I nogen grad
☐ I høj grad
☐ I meget høj grad
☐ Ved ikke
☐ Ikke relevant

Din omgangskreds

18. Hvilke personer husker du, at du havde den tætteste relation til i dit liv inden skaden, og hvor ofte havde du kontakt med dem? *(Nævn fulde navn og relation (fx. søster, kollega eller lignende) til den du havde den tætteste relation til som nr. 1, den du har den næsttætteste relation til som nr. 2 osv. Du må nævne så mange, som du vil)*

	Dagligt	**Ugentligt**	**Månedligt**	**Sjældnere end hver måned**	**Andet**	**Ved ikke**
1. ________________	☐	☐	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐	☐	☐
10.________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

19. Hvilke personer (angiv med fulde navn) har du den tætteste relation til i dag, og hvor ofte har du kontakt med dem?

	Dagligt	Ugentligt	Månedligt	Sjældnere end hver måned	Andet	Ved ikke
1. ____________________	☐	☐	☐	☐	☐	☐
2. ____________________	☐	☐	☐	☐	☐	☐
3. ____________________	☐	☐	☐	☐	☐	☐
4. ____________________	☐	☐	☐	☐	☐	☐
5. ____________________	☐	☐	☐	☐	☐	☐
6. ____________________	☐	☐	☐	☐	☐	☐
7. ____________________	☐	☐	☐	☐	☐	☐
8. ____________________	☐	☐	☐	☐	☐	☐
9. ____________________	☐	☐	☐	☐	☐	☐
10.____________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

20. Hvem (angiv med navn) vil du spørge om hjælp i forbindelse med udfordringer i hverdagen?

	Børnepasning	En nødsituation (hospitalsindlæggelse, pengenød mv.)	Praktiske ting (Vande blomster, tømme postkasse, opbevare nøgle, flytning, indkøb, madlavning, rengøring, computerproblemer)	Hjælp til at udfylde formularer, blanketter, skemaer osv.
1. ________________	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐
10.________________	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

21. Hvem (angiv med navn) vil du søge hjælp hos i forbindelse med udfordringer i hverdagen?

	Helbredsmæssige	Arbejdsmæssige	Familiemæssige	Personlige
1. ________________	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐
10.________________	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

22. Hvem (angiv med navn) beder du om hjælp i forbindelse med rehabiliteringsforløbet?

	Udfyldelse af papirer til kommunen osv.	**Kommunikation med fagpersoner**	**Økonomiske forhold**	**Følelsesmæssige udfordringer**	**At besøge den unge tilskadekomne**
1. ________________	☐	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐	☐
10.________________	☐	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

Rehabiliteringsforløbet

23. Har du den viden du har behov for i forbindelse med rehabiliteringsforløbet?

- ☐ Slet ikke
- ☐ I mindre grad
- ☐ I nogen grad
- ☐ I høj grad
- ☐ I meget høj grad
- ☐ Ved ikke

Uddyb gerne hvilken viden du har brug for og i hvilken grad du oplever, at du besidder den viden?

____

____

24. Hvor ofte bruger du forskellige videnskilder i forbindelse med rehabiliteringsforløbet?

	Aldrig	**Sjældent**	**Af og til**	**Ofte**	**Meget ofte**	**Ved ikke**
Venner, familie, bekendte	☐	☐	☐	☐	☐	☐
Egen læge eller andre fagpersoner	☐	☐	☐	☐	☐	☐
Internet, medier, reklamer mv.	☐	☐	☐	☐	☐	☐
Personlige erfaringer eller viden	☐	☐	☐	☐	☐	☐
Andet	☐	☐	☐	☐	☐	☐

Uddyb gerne hvordan?

____

____

25. Har du benyttet dig af "Hjerneskadeforeningen" eller andre patientforeninger under rehabiliteringsforløbet?

- ☐ Ja
- ☐ Nej
- ☐ Ved ikke

Hvis ja – hvilke og til hvad?

____

____

26. Oplever du, at du har den hjælp og støtte du har behov for i forbindelse med rehabiliteringsforløbet?

- ☐ Slet ikke
- ☐ I mindre grad
- ☐ I nogen grad
- ☐ I høj grad
- ☐ I meget høj grad
- ☐ Ved ikke

Uddyb gerne hvad, hvordan og af hvem?

____

____

27. Har der i rehabiliteringsforløbet været nogle tiltag, som har hjulpet/støttet dig?

- ☐ Ja
- ☐ Nej
- ☐ Ved ikke

Hvis ja – hvilke og hvordan har de hjulpet dig??

____

____

Afslutning

Har du yderligere bemærkninger til nogle af spørgsmålene i spørgeskemaet?

____

____

Tak for besvarelsen!

SURVEY 1½ YEAR AFTER DISCHARGE – RELATIVES

Kære pårørende til den unge

Tak fordi du deltager i undersøgelsen *" Et stop på vejen og det sociale netværks betydning for unges rehabiliteringsforløb og livssituation efter en erhvervet hjerneskade"*.

Som en del af undersøgelsen vil vi bede dig om at svare på nedenstående spørgeskema.
Spørgsmålene omhandler blandt andet dine relationer, hvor du vil blive bedt om at oplyse fulde navne. Navnene vil kun blive brugt i analysesammenhæng og vil herefter blive slettet. Alle oplysninger vil blive behandlet fortroligt og data (herunder alle navne) vil blive slettet, når de er færdiganalyseret.

For yderligere oplysninger om undersøgelsen stiller Mette Ryssel Bystrup sig gerne til rådighed samt henvises til den udleverede informationsfolder.

Mange tak for besvarelsen!

Dato: ________________

Generelle oplysninger

1. **Relation til den unge?**
    - ☐ Forældre
    - ☐ Ægtefælle eller samlever
    - ☐ Søn eller datter
    - ☐ Anden familie
    - ☐ Ven
    - ☐ Nabo
    - ☐ Kollega
    - ☐ Anden relation (skriv hvilken)? ________________
    - ☐ Ved ikke

2. **Har din bo- og samlivssituation ændret sig siden ulykken?**
    - ☐ Ja
    - ☐ Nej
    - ☐ Ved ikke

Hvis ja, hvordan?

____

____

3. **Har din beskæftigelsessituation ændret sig siden ulykken (fx orlov, sygemelding, jobskifte)?**
    - ☐ Ja
    - ☐ Nej
    - ☐ Ved ikke

Hvis ja, hvordan?

____

____

4. I de sidste 7 dage... Hvor meget indvirkede den unge tilskadekomnes situation din arbejdsindsats på dit arbejde?

☐ Overhovedet ikke
☐ I mindre grad
☐ I nogen grad
☐ I høj grad
☐ I meget høj grad
☐ Ved ikke
☐ Ikke relevant

5. I de sidste 7 dage... Hvor meget indvirkede den unge tilskadekomnes situation dig i dine øvrige daglige aktiviteter?

☐ Overhovedet ikke
☐ I mindre grad
☐ I nogen grad
☐ I høj grad
☐ I meget høj grad
☐ Ved ikke
☐ Ikke relevant

Din omgangskreds

6. Hvilke personer (angiv med fulde navn) har du den tætteste relation til i dag, og hvor ofte har du kontakt med dem *Nævn fulde navn og relation (fx. søster, kollega eller lignende) til den du havde den tætteste relation til som nr. 1, den du har den næsttætteste relation til som nr. 2 osv. Du må nævne så mange, som du vil)*?

	Dagligt	**Ugentligt**	**Månedligt**	**Sjældnere end hver måned**	**Andet**	**Ved ikke**
1. ________________	☐	☐	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐	☐	☐
10.________________	☐	☐	☐	☐	☐	☐

Yderligere personer

____

____

7. Hvem (angiv med navn) vil du spørge om hjælp i forbindelse med udfordringer i hverdagen?

	Børnepasning	**En nødsituation (hospitalsindlæggelse, pengenød mv.)**	**Praktiske ting (Vande blomster, tømme postkasse, opbevare nøgle, flytning, indkøb, madlavning, rengøring, computerproblemer)**	**Hjælp til at udfylde formularer, blanketter, skemaer osv.**
1. ________________	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐
10.________________	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

8. Hvem (angiv med navn) vil du søge hjælp hos i forbindelse med udfordringer i hverdagen?

	Helbredsmæssige	Arbejdsmæssige	Familiemæssige	Personlige
1. ________________	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐
10.________________	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

9. Hvem (angiv med navn) beder du om hjælp i forbindelse med rehabiliteringsforløbet?

	Udfyldelse af papirer til kommunen osv.	**Kommunikation med fagpersoner**	**Økonomiske forhold**	**Følelsesmæssige udfordringer**	**At besøge den unge tilskadekomne**
1. ________________	☐	☐	☐	☐	☐
2. ________________	☐	☐	☐	☐	☐
3. ________________	☐	☐	☐	☐	☐
4. ________________	☐	☐	☐	☐	☐
5. ________________	☐	☐	☐	☐	☐
6. ________________	☐	☐	☐	☐	☐
7. ________________	☐	☐	☐	☐	☐
8. ________________	☐	☐	☐	☐	☐
9. ________________	☐	☐	☐	☐	☐
10.________________	☐	☐	☐	☐	☐

Andet (hvem og hvad)?

____

____

Afslutning

Tak for besvarelsen!

SURVEY ½ YEAR AFTER DISCHARGE – PROFESSIONALS

Kære fagprofessionelle til den unge

Tak fordi du deltager i undersøgelsen ”Et stop på vejen?” under projekt ”Bristede drømme – nyt håb”.

Som en del af undersøgelsen vil vi bede dig om at svare på nedenstående spørgeskema.
Alle oplysninger vil blive behandlet fortroligt og data vil blive slettet, når de er færdiganalyseret. Dine svar vil blive anonymiseret inden de anvendes i undersøgelsen.

For yderligere oplysninger om undersøgelsen henvises til den vedlagte, og tidligere udleverede, informationsfolder "Et stop på vejen?"

Du bedes besvare spørgeskemaet hurtigst muligt og maile det til **metbys@rm.dk.**

Mange tak for besvarelsen!

Dato: _________________

Generelle oplysninger

1. **Køn**
    - ☐ Mand
    - ☐ Kvinde

2. Alder __________ år

3. Hvad er din uddannelse?

☐ Pædagog

☐ SOSU

☐ Læge

☐ Sygeplejerske

☐ Fysioterapeut

☐ Ergoterapeut

☐ Talepædagog

Andet? ____

4. Hvornår blev du færdiguddannet?

____

5. Hvor længe har du arbejdet på din nuværende arbejdsplads?

____________________________ mdr./år

6. Hvor mange års erfaring har du samlet set ifht. at arbejde med mennesker med en hjerneskade?

____________________________ mdr./år

7. Relation til den unge?

☐ Kontaktperson

☐ Team

Andet? ____

Din primære opgave i forhold til den unge?

____

8. Hvor lang tid har du arbejdet med den unge?

☐ Under 3 måneder

☐ 4 -6 måneder

☐ 7-9 måneder

☐ 10-12 måneder

☐ 13-15 måneder

☐ Mere end 15 måneder

Afslutning

Har du yderligere bemærkninger til nogle af spørgsmålene i spørgeskemaet?

____

____

Tak for besvarelsen!

Paper 1

Bystrup, M. R., Larsen, K., Hindhede, A. L., Pallesen, H., Aadal, L., & Feiring, M. (2018). Outline of a History of Neurorehabilitation in Denmark–a Sociological Perspective. *Praktiske Grunde 3-4*.

Outline of the History of Neurorehabilitation in Denmark – a Sociological Perspective

Mette Ryssel Bystrup, Kristian Larsen, Anette Lykke Hindhede, Hanne Pallesen, Lena Aadal & Marte Feiring

This article unravels the genesis and history of neurorehabilitation (NR) in Denmark in order to understand the transformation that this subfield has undergone since the 1970s and how this is reflected in the present structure. Seen through the lens of Bourdieu's concept of field and based on a document review strategy of historical sources and political documents the article constructs three analytic periods: 1. the genesis of NR until the first half of the 1980s, 2. the institutionalization of NR from 1985-2006 and 3. the political restructuring of NR after the local government reform in 2007. Our analysis shows that NR is a multi- and interdisciplinary practice characterized by heterogeneity, although with growing homogeneity in clinical practice due to an increased number of NR institutions, and later political guidelines. We conclude that despite an increased power to psycho-social and comprehensive approaches, biomedical knowledge is still dominant and reflected in doxa.

Keywords: Denmark, Field, History, Neurorehabilitation, Social positions, Structure

Introduction

Across Scandinavian societies, we see current transformations of welfare state institutions and conditions for patients, relatives, professionals and politicians (Højbjerg and Martinussen 2016). These transformations are also evident in institutions and practices related to neurorehabilitation (NR). NR is an example of a professional practice attempting to monopolize the knowledge of how to handle people (Carlhed 2007, 42) – in this case people affected by brain injury. In Denmark (population 5.7 million), 22,000 people acquired a brain injury in 2015, and it is estimated that at least 120,000 Danes live with the consequences of disability after brain injury, affecting the lives of patients and their relatives in different ways (National Audit Office 2016). The number of post-brain-injury individuals has increased over the years due to new treatment possibilities and thus increased survival (Borg et al. 2011). The Danish welfare state provides free health care services for all citizens, regardless of their income (Ministry of Health 2016). NR services are often technologically advanced, relative to the complexity and comprehensiveness of the brain injury, and may involve many different and specialized healthcare professionals. Due to the large number of people affected by a brain injury, NR is a heavy expenditure for the welfare state (National Board of Health 2011).

In the wake of the Local Government Reform in 2007[1] NR practice has been critised by the state and the regions, documenting challenges with the organization of services entailing lack of coherence, uneven quality of rehabilitation practices (National Board of Health 2011; Danish Regions 2011; Ministry of Economic Affairs and the Interior 2013). These post 2007 criticisms have been followed up by several financial grants to the regions and municipalities to strengthen their services. However, despite both ongoing criticism and the distribution of grants, a recent National audit (2016) states that these challenges are still pertinent.

When studying complex social transformations such as NR, we consider a Bourdieuan field perspective applicable. Bourdieu studied many social fields, including the cultural field of art (Bourdieu 1996a), the academic field (Bourdieu 1988) and the economic field (Bourdieu 2005). He did not analyze the field of health care or of rehabilitation. Recently however, Pinell and Jacobs (2011) have undertaken a Bourdieuan-inspired analysis of the medical field in the 19th century in France where they construct three spaces: Clinical medicine, social medicine, and auxiliary sciences - and investigate the relation between these spaces. Other scholars have focused on rehabilitation in the Scandinavian welfare states from a Bourdieuan perspective: Carlhed's (2007) historical analysis of habilitation practices on the development of the Swedish health care system identifies an alliance between the state and the medical profession; Feiring and Solvang's (2013) study of the formation of rehabilitation identifies a shift from a biomedical to a broader medical and social orientation; and Larsen's (2003) analysis of power structures among health professions in a Danish context shows how biomedical disciplines retain their power bases. In addition, Guldager et al (2018) construct the concept 'rehabilitation capital' as an individual or family resource that is valued in the field of rehabilitation and consists of physical, behavioral and cognitively embedded attitudes and practices.

In order to approach an understanding of the transformations and structuring including challenges of NR, our aim is to unravel the genesis and history[2] of NR practices in Denmark, analyzed as products of welfare state polices, practices and knowledge development hence relations of domination between positions reflected in comprehensive NR practices. Our research questions are:

Who were the main historical agents and positions in NR and how did they gain influence? How did these diverse positionings materialize and become reflected in the doxa (common beliefs) of NR? Which other fields have influenced NR and its knowledge-practices, and relative autonomy?

To address these questions, we have constructed three periods: Period 1, the genesis of NR until the first half of the 1980s; period 2, the institutionalization of NR from 1985-2006, and finally, period 3, the political restructuring of NR after the local government reform in 2007. These periods are constructed with reference to central events, interventions, and changes in power dynamics between the main agents and positions. The two main historical positions are identified as the biomedical (orthodox) and a more psychosocial (heterodox) position. A discussion then follows of each period, based on key elements of Bourdieu's field concept. Finally, we relate NR to its boundary fields.

Methodology

The theoretical approach is inspired by Bourdieu and Wacquant's concept of field (1992), which they describe as an analytical mind-set, consisting of a configuration of objective relations between positions. The relational force between the positions generates internal dynamics and defines the structure of the field. Wacquant and Akcaoglu (2017, 62) clarify the relation between Bourdieu's concept of social space and field in the following manner: *social space* is the mother category, whereas *field* is a specialized social space if it "becomes sufficiently demarcated, autonomized, and monopolized".

Bourdieu operates with open concepts in order to break with positivism, thus he does not operate with clear definitions or methodological guidelines. In order to operationalize the concept of field, we have consulted Broady's (1998) rules of thumbs. Of these, the following areas are especially relevant for our analysis: The structure of the field defined by polarities; a space of possibilities and its homology with the social space; doxa (own beliefs) and own institutions. Bourdieu's approach includes identifying conflicting relationships and heterodox positions struggling for recognition and challenging the orthodox (traditional) positions; symbolic violence; discussing specific logics, doxa, and symbolic economies (capitals) distinctive within NR; and evaluating the degree of relative autonomy in the sense of inside steering versus outside dominance from external fields (Bourdieu and Wacquant 1992). External dominance might for instance be exerted from forces within the political (or bureaucratic) field with demands of reporting, instructions to be followed, guidelines, and economic framing such as rates based on diagnosis-related groups (DRG's). These Bourdieuan concepts are then applied as analytical tools supported by a conceptualization of rehabilitation in late modern society (Hanssen and Sandvin 2003) hence vertical and horizontal pressures on rehabilitation practices. We will not conduct a fully-fledged field analysis based on a correspondence analysis of quantifiable data on types and volumes of capitals etc. This is in line with Wacquant and Akcaoglu (2017) who argue for a less rigid and method-defined way of analyzing fields and subfields. Unlike conventional historical analysis, we will not create a linear progression of events, but will rather focus on the struggles and forces in the field. Each section of this analysis focuses on developments that emerge as alliances and / or conflicts between positions, which then claim authority based on their differing capital (e.g. cultural, economic and social) in NR.

The initial identification of central historical agents and events was provided through a document review strategy of the 'anthropological composition' of NR (Løvschal Nielsen 2004) on various agencies in NR, including hospitals, rehabilitation institutions, and user organizations. This, along with the sociological work of Delica (2007) was used to identify the administrative and organizational changes for professionals working with persons with brain injuries. This created the basis of the two analytical periods (1 and 2) based primarily on primary and secondary texts, as well as a historical perspective presented in more current political documents.

This revealed that NR was an area of increasing political interest (and steering). A second purpose of this first review process was therefore to identify political documents in order to identify the main political authorities in these early two phases of NR. This identification of central political authorities was continued by a second review based on the two most recent disease management programs published by two different political authorities (the Danish Health Authority and Danish National Board of Social Services) in NR, as well as an audit from the National Audit Office of Denmark (NAOD). This was undertaken in order to identify relevant current political documents (legislation, announcements, guidelines, reports) and authorities, as well as creating an overview of changes in political intervention throughout the years. This second review formed the basis of constructing period 3. The documents identified through both the first and the second review process were further classified and selected according to the following criteria: (1) documents representing the public sector for the whole country concerning brain injury service provision for adults; (2) documents issued from political and professional authorities; (3) documents related to the rehabilitation of *acquired* brain injury; (4) documents concerning adults. General legislative documents (for example changes in health legislation) were excluded despite their possible influence on NR. In total 31 political documents were located (marked with (*) in the list of references). A systematic approach, as described by Kropp (2009) and Delica and Mathiesen (2007), was applied to form the basis of the registration of the documents.

We registered the same information per document: year, author, type of document, objective/purpose, target group, the context of the document, and potential impact on NR. Three key documents were selected for further detailed analysis aimed at exploring the dominant social positions from a contemporary perspective in period 3. The three documents were selected because the overview of documents revealed these were authored by the primary authorities in NR representing different approaches and being the most contemporary, comprehensive as well as regulative published. The documents are:

- National Board of Health (2011) "*Brain Injury - A Health Technology Assessment*" (HTA)
- Danish Health Authority (2011) "*Disease Management Program of Rehabilitation of Adults with an Acquired Brain Injury"* (DMP) [Author's own translation]
- Danish National Board of Social Services (2016) "*Disease Management Description: Rehabilitation of Adults with a Complex Acquired Brain Injury – In the most Specialized Social and Special Teaching Area"* (DMD) [Author's own translation]

Period 1: The genesis of neurorehabilitation

As recently as the 1970s, the dominant understanding of neurology was that brain tissue was not repairable, and therefore a brain injury was considered more or less a permanent condition.

> It was not until the 1980s that it was recognized that the rehabilitation of people with brain injuries is possible […] Earlier, efforts directed towards this patient group were characterized by a high degree of pessimism. The majority of brain-injured individuals were given no training. [Author's own translation] (National Board of Health 2011, 72)

Prior to the 1980s, the main treatment plan was testing the brain-damaged person, making a diagnosis, and offering care, while the training of cognitive functioning was not an objective and was instead perceived as futile. On the whole, there were three types of institutions treating patients with brain injury: somatic hospitals, psychiatric hospitals, and physical-medicine hospitals or clinics. After discharge from hospital, only a few institutions were involved in the treatment of people with brain injury, and instead most people were referred to nursing homes for the elderly (or younger physically disabled) or physically placed among the mentally ill. Training was primarily carried out by therapists who based their approaches on orthodox therapeutic principles, while nurses were in charge of caring. At physical hospitals, physicians (and physiotherapists) were responsible for medical training, and social counselors assisted in managing hospital discharge, education, and job training (Løvschal Nielsen 2004).

During the 1970s, the medical orthodox position was challenged by neurologists in several countries, most notably the Soviet Union, Germany, and the USA. They possessed embodied cultural capital (e.g. medical language usage and natural science codex) acquired from medical education (institutionalized cultural capital) (Bourdieu 1986), which was transformed into new theories and research about the brain. The Soviet neurologist and psychologist Alexander Luria (1902 -1977) was one of the pioneers in neuropsychology. Luria was educated in both medicine and psychology, his father a professor of medicine and his mother a dentist (indicating that he came from a cultural elite in Russia). He was famous for integrating neurology and psychology (with pedagogical inspiration from his cooperative work with Lev Vygotsky) (Homskaya 2001). Lurias' approach considered psychological processes in the nervous system to be *social* and *cultural* in their origin and structured through speech; he claimed that it was the influence of the outside world that made the brain into a complex functioning system (Luria 1972). The main purpose of this perspective was to situate the individual in a cultural and social context. In addition, Polish-German scientist Kurt Goldstein (1878 – 1965) was educated in medicine and held positions as a neurologist and a psychiatrist. He is known for his creation of a holistic theory of the organism aimed at people who acquired a brain injury during World War I (Goldstein 1939). He pioneered the creation of a coherent treatment system and brought this knowledge to New York, where this neuropsychological approach was further disseminated (Teuber 1966). Scholars from the USA, Switzerland, and Germany started applying therapeutic methods and pedagogical principles that challenged the biomedical approach. This challenge was also directed at scientific methods where neuropsychological experiments were being rejected by the medical position and instead explained as spontaneous recovery (Teuber 1966; Løvschal Nielsen 2004).

The neuropsychologist Anne-Lise Christensen and her colleagues introduced this neuropsychological approach to Denmark in the 1980s. They conducted experiments on the treatment of people with brain injury, utilizing an interdisciplinary and comprehensive approach. These treatments involved sociocultural relations by providing training in everyday life matters and relationships, and including pedagogical approaches. This was met with distrust at the medical hospitals in Denmark, representing the orthodox position, as it was considered non-objective in nature and therefore invalid (Christensen et al 1989; Christensen 2013; Løvschal Nielsen 2004).

The challenge of providing legitimate research results for these newcomer rehabilitation approaches (heterodox positions) to brain injury within biomedical research traditions was also addressed by the County Council Association (1991), which at the time related to the limited resources provided for these new treatment and research forms.

A further branching out of new approaches challenging the relations of dominance followed these neuropsychological breakthroughs. These applied to larger groups of patients and continued to break with traditional biomedical approaches well into the 1990s. Examples of areas where these cultural/theoretical advances were converted in clinical practice are: speech therapy, special education, psychotherapeutic and pedagogical principles and approaches. The *Therapie Zentrum Burgau* in Germany influenced some of these therapies, with its principles of early intervention for retraining, a multidisciplinary approach, and the use of specific training models (such as neuro-developmental treatment). These rehabilitation approaches were brought to Denmark and were practiced in multidisciplinary teams that challenged the monopolistic practices of medical doctors (Kjærsgaard 1993; Løvschal Nielsen 2004). This change in practice was helped along by increased knowledge regarding brain plasticity, which also inspired the development and trial of new treatment paradigms (Borg et al. 2011). General clinical practice was relatively stable during this period, but inspiration and theories from psychology and pedagogy started to shape preconditions and inspired both individuals and institutions to rethink their practices for this group of patients (Angelsø and Smed 1980). Interventions were for the most part still fragmented, patchy, and individual based however (County Council Association 1991). To sum up, the genesis of NR was a product of new ideas and knowledge, involving various struggles among professions such as medical doctors constructing the orthodox position and professions such as neuropsychologists, speech therapists, special education teachers and psychotherapists taking a heterodox position.

Period 2: Institutionalization of neurorehabilitation

In the 1980s, structural changes at the political level led to struggles concerning the classification and identification of individuals with brain injury as a ‘new’ patient group, as well as a selecting of responsible institutions for providing services. The running of the state social care system was delegated to county authorities, which were tasked with the care of all disabled persons (National Board of Health 2011). This led to long-lasting negotiations, concerning which political authorities (social or health) should be responsible for brain injuries, as well as whether this kind of disability should be considered a physical or psychological handicap (County Council Association 1991; Feiring 2016). This period is characterized by a jostling for positioning in defining how the injured brain should be conceptualized and approached, how doxa should be defined and which kind of symbolic capital should be valued in NR. This search for common principles can be considered a formation of a subfield[3] (Gorski 2013).

The heterodox position based on neuropsychological and pedagogical approaches to brain injury was manifested and materialized with the establishment of the two rehabilitation centers in 1985: Vejle Fjord Rehabilitation Centre, and the Centre for Rehabilitation of Brain Injury. The latter was privately funded and established at the University of Copenhagen's psychology department, rather than at the Copenhagen University Hospital, where this new approach met resistance from medical professors (Løvschal Nielsen 2004). The psychological department was the first institution of its kind in Europe, anchored in neuropsychological methods. Besides neuropsychologists, the staff included speech therapists, physiotherapists, occupational therapists, and special teachers, thus providing an interdisciplinary and comprehensive approach (Christensen 1984; Christensen 2013). Vejle Fjord Rehabilitation Centre was a specialized hospital with a history of offering treatment for specific illnesses over the years depending on demands. They offered interdisciplinary practice where treatment combined psychotherapy with cognitive rehabilitation, physical and occupational therapy, and work training (Vejle Fjord 2018; National Board of Health 2011).

In the years following their foundation, another five public post-hospital rehabilitation centers for individuals with brain injuries were established and organized at a county level and approved by the Ministry of Social Affairs. The inclusion of socio-psycho-cultural dimensions as well as the inclusion of the physical surroundings (e.g. the natural surroundings as part of the rehabilitation in some of the centers) across these rehabilitation centers differed from previous treatment programs, which focused solely on the injured biological body and brain, within traditional (somatic) hospitals in the general medical and neurological departments (National Board of Health 2011; Christensen 2013; Vejle Fjord 2018).

A national knowledge center for brain injury was established in 1994 in order to support the counties, by collecting, processing, and communicating information and knowledge. The knowledge center represented the new heterodox approach, expressed through the production of knowledge and expertise via websites, databases, courses, the creation of county brain injury teams, a magazine named *Fokus,* projects and funding in collaboration with the Ministry of Social Affairs. Overall, this new knowledge center contributed to increasing new knowledge on NR, in relation to brain injuries, regarding psychological, pedagogical and social aspects. On the international scene, the Danish knowledge center played a significant role, arranging conferences and seminars that attracted prestigious collaborators (Andersen 2006; IBIA 2019; Løvschal Nielsen 2004)[4]. During the 2007 local government reform, the knowledge center was transformed into what is now known as VISO[5]: a national knowledge and specialist consultancy (but with no decision-making authority) in relation to social areas and the education of special requirements for all kinds of handicaps. VISO continues to be run by Danish National Board of Social Services (Ministry of Social Affairs 2006; Andersen 2006).

The seven new neurorehabilitation centers for patient treatment and the national knowledge center increased the power of the heterodox position under the social authorities. This was further strengthened with the establishment of Danish Neuropsychological Society (DNS 2018) in 1988 and Danish Neuropedagogical Society, (DaNS 2018) in 2001, both of which are communities for professionals.

After almost 20 years of consolidating the heterodox positioning by an increased number of agents and institutions as well as a re-establishing of educational capital and practices, the orthodox position underwent a revival around the year 2000, especially with the establishment of two specialized hospital units with nationwide coverage (Danish Health Authority 1997). The biomedical approach was materialized in hospitals under the health authorities. However, these hospitals included more professionals in e.g. psychology and social pedagogy than at the previous traditional somatic hospitals. In addition, several mono-professional societies (psychologists, physiotherapists, nursing and occupational therapists) with a focus on neurorehabilitation had expanded their mandates with course activities and education services. Also, patient preferences, needs and wishes for the future received much greater focus in both hospital-based and municipal rehabilitation (Andersen 2006; Løvschal Nielsen 2004; VCR 1988). This may all be seen as an example of the growing recognition of heterodox approaches and a gradual transformation of the traditional treatment of the brain injured. The medical positioning within NR was further strengthened in 2007 by the establishment of a medical professorship in NR at the University of Aarhus, constituting symbolic capital. This also reinforced the production of scientific research on NR based on biomedical research traditions (National Board of Health 2011).

The voices of patients and their affected relatives were also further institutionalized and strengthened over the years through the establishment of user organizations. Since 1985, people with brain injuries have been unified as one group of disabled, represented by user organizations. User organizations in Denmark have increasingly been strengthened due to legislation providing them with increased power and involvement in the development of new legislation and initiatives (Bonfils and Bangshaab 2012), as well as a reinforced international coorporation (Froestad and Ravneberg 1991). User organizations have lobbied for the opinions and experiences of patients and their relatives to be taken into account, as well as for more social-oriented approaches. Another increasingly active and powerful agent representing patients and relatives is the media (Danish Regions 2011). The media has questioned the organization of NR services and generated an increased focus on patient (and relatives) perspectives (DR1[6] 2012). In addition, trade unions also entered into the NR discussions in the 1980s because of brain injuries caused by solvents. These agents provided services/interventions outside the hospital with a much greater focus on social and cultural dimensions, which have influenced treatment and rehabilitation (County Council Association 1991). Moreover, additional political organs were established, such as DUKH, the Impartial Consultative Service for People with Disabilities, an institution under the Ministry of Social Affairs established in 2002, operating as a consulting service which offers impartial support for the disabled and people around them (DUKH 2018). These groups and societies have played an important role in drawing NR towards their agendas (Borg et al. 2011).

Correspondingly, arenas for co-operation and fusion of divergent authorities and other agents and appertaining logics are evident. An example is a white book from 2004, which is a Danish translation and interpretation of the World Health Organization's (WHO) conception of health and disability, and is thereby embedded in a health/medical context (WHO 2002). The collaborators creating the white book were different professional societies and corporations, who defined the deliberate national framing of rehabilitation approaches in Denmark. Notably, the Ministry of Social Affairs is the only national-level political authority represented in this context, as the Ministry of Health is absent (although the health and medical position is still strongly represented by professional societies and institutions). This may have left space for an interdisciplinary and comprehensive approach to rehabilitation, which is also expressed by the white book's emphasis on the International Classification of Functioning, Disability and Health (ICF) (Marselisborg Centre 2004). The ICF is promoted as a biopsychosocial model aiming to unite biological, psychological, and social approaches and thereby create a more composite understanding of illness and disability (WHO 2002). Not only did ICF provide a common language for the increased number of professionals working in NR, but it also helped generate a broader understanding and increased attention on rehabilitation (Schrøder and Schultz Petersen 2012). This all increased the autonomy of the subfield of NR (Gorski 2013).

Period 3: Political restructuring of neurorehabilitation

In 2007, a reform of the local government structure was implemented in Denmark, which gave the responsibility for NR (following hospital treatment) to the 98 municipalities, instead of the 14 counties. This decentralization of rehabilitation services, together with changes in the Health Act in 2006, gave a more health-oriented responsibility and authority to the municipalities. In addition, the position of disabled citizens was strengthened because of changes in legislation, making it compulsory for the municipalities to consult people with disabilities and their associations about policies and services (Ministry of Interior and Health 2005; Bonfils and Bangshaab 2012).

The government reform also occurred at the time of the global financial crisis that struck the country. This led to cost-cutting in the public sector and contributed to the reduction of a number of specialized rehabilitation institutions that had long-term experience and skills and were previously run by the counties. According to the regional authorities, this weakened the knowledge base and led to de-specialization of NR services (Danish Regions 2011). One response to this criticism has been the increased state regulation of NR, primarily from the Danish Health

Authority (e.g. documents concerning knowledge and practices) and a demand for research-based practices (National Board of Health 2011; Danish Health Authority 2011; National Board of Social Services 2016). This increased state involvement became visible in the overview of documents we found during the review process showing that the total number of publications had increased throughout the years with an additional boost after 2007. The majority of documents were published by political health organizations, showing that these have played a central role (both before and after 2007). The political health organizations primarily consist of the Ministry of Health and the Danish Health Authority (itself consisting of many professionals with medical backgrounds). The former prepares legislation relating to the work of healthcare practitioners, whereas the latter is the author of the Health Technology Assessment and Disease Management Program. The political social position was first recognized through documents published by the County Council Association and more previous by Danish National Board of Social Services taking over authority from the counties after 2007. Additionally, the total number of political authorities (those concerning employment and special education) increased after 2007. We suggest that this increased activity of social political authorities as well as the increased total number of active political authorities likely came with an enhanced understanding of the complexity of the disability, hence the interventions as well as the need of a multidisciplinary approach. The involvement from social and educational authorities maintained a focus on the life conditions of those with brain injuries, ways of living with the disabilities and a greater need for cooperation (e.g. County Council Association 2016; Danish National Board of Social Services 2016).

One of the central documents representing the health authorities ‘The clinical guideline, Health Technology Assessment (HTA)’ is described as a systematic, critical, and comprehensive report based on research in order to find the ‘best available evidence’ for treatment. The project group behind the Health Technology Assessment consists of practitioners (from hospitals, the Centre for Rehabilitation of Brain Injury, and municipalities), universities, and the Danish Health Authority: hence altogether a strong representation of medical/health-oriented agents (e.g. via different medical societies). Within the HTA, the biomedical and positivistic methodology (e.g. the notion of knowledge gathering, systematic literature reviews, and economic calculations) where evaluation of effects, quantitative studies, and evidence-based interventions are given a seal of approval. In comparison, the neuropsychological and holistic interventions are referred to as a more doubtful approach: ”There is weak to moderate evidence for effect of multidisciplinary rehabilitation programs in the form of holistic neuropsychological programs in the sub-acute/chronic phase” [Author’s own translation] (National Board of Health 2011, 12).

Despite the HTA’s approval of biomedical treatments and standards, the document claims to be based on the ICF with its biopsychosocial approach and the need for a more comprehensive approach in neurorehabilitation “including assessment of the need of the citizen’s need for interdisciplinary rehabilitation, hence physical, cognitive, emotional, pedagogical and social aspects" [Author's own translation] (National Board of Health 2011, 203).

The 'Disease Management Program' is based on the Health Technology Assessment and is a service guide for practitioners. The author group behind the Disease Management Program primarily represents scientific and (medical) professional societies, political authorities (Danish regions and municipalities), and user organizations. Despite the interdisciplinary group behind the Disease Management Program, the political health authorities and professional medical societies are most strongly represented. However, compared to earlier documents from the Danish Health Authority (for example Danish Health Authority 1997), the author group behind this Disease Management Program opened up to also include agents representing more psycho-social approaches (e.g. represented by VISO and Centre of Brain Injury) and political authorities, as well as the increased number of different participants. This diversity has left its mark with attempts towards a comprehensive and social-oriented approach (for example in the interventions described). Examples of this are an increased awareness of the social aspects of disabled life, such as communication, occupation, relations, etc.

The Danish Health Authority has also channeled economic resources to NR via SATS-funding.[7] In 2011, NR was provided 150 million DKK over a four-year period to strengthen the municipalities, in order to increase their knowledge and the specialization of NR services. In 2012, 100 million DKK was provided to strengthen the regional interventions for young people with an acquired brain injury (National Audit Office of Denmark 2016). This is evidence both of the increased involvement from the political and economic field in NR from 2011 onwards and of how NR is being politically viewed as an area of health with the Danish Health Authority as a distributor.

In 2016, the National Board of Social Services published the Disease Management Description. This document was developed in cooperation with political actors at national, regional and municipality levels, with divergent knowledge profiles. Four different authorities were included, representing employment, education, health and social relations, and rehabilitation centers; while the professional experts were mainly represented by therapists and neuropsychologists, as well as a few with a pedagogical and medical background. The user organizations were represented in an end-user stakeholder group. A psycho-social approach is predominant in this document, where user involvement, neuropedagogy, and neuropsychology are seen as preparing the ground for cooperation between institutions and professionals. Despite a relatively small medical representation, the Disease Management Description is based on the Health Technology Assessment, the Disease Management Program and previous statements that reveal underlying biomedical logic: "The National Board of Health recommends that efforts are knowledge-based. That is, the highly specialized offers and knowledge environments' systematic documentation of the evidence of the methodological effect" [Author's own translation] (National Board of Social Services 2016, 7).

Biomedical terminology is also evident in the use of terms such as *disease* (with implications of diagnosis), rehabilitation post *hospital* (where the clinical hospitals are considered the dominant arena), and a focus on the *individual body* and the diagnosing of its *functional capacity*. However, the professional approach reveals its foundation in a more heterodox tradition with ‘neuropedagogy’ and ‘neuropsychology’ being appointed their own sections in the document (National Board of Social Services 2016). The representation of universities also shows the increased requirement to legitimize knowledge.

The supplying of economic capital to NR through the social political authority dates back to before the political restructuring in 2007. In 1998 55 million Danish kroner was allocated to the area of brain injury through SATS-funding administrated by the Ministry of Social Affairs (Andersen 2006). This shows that NR was politically considered a *social* area in the beginning, and not until many years later (predominantly from 2011 and onwards) was it considered and prioritized as a health area.

The increased political intervention, prioritizing and investment in NR can be explained due to the internal strengthening described in the section of the institutionalization of NR but also due to better technology and treatment possibilities, better outcomes for patients and therefore also extended cost for the welfare state because of treatment and care.

DISCUSSION

The entering of a heterodox position

The primary historical positions have been constructed as a biomedical (orthodox) position and a psycho-social (heterodox) position, representing an interdisciplinary and comprehensive approach. The dominant biomedical agent’s definition of symbolic capital represented what was appreciated in NR, hence what was required by the heterodox newcomers (Bourdieu and Wacquant 1992). The most validated heterodox agents (e.g. Luria and Goldstein) held symbolic authority because of their possession of symbolic capital - primarily cultural capital (being educated medical doctors and therefore understanding the embodied knowledge of medicine such as the biomedical language, classifications, theories, etc). This was of importance for the power they were able to claim and their ability to gain influence. In a Danish context, the NR pioneers also possessed convertible capital. Anne-Lise Christensen, for example, held valuable social capital (her husband being a university professor with family ties to the Egmont family and foundation; educated in prestigious institutions and milieus such as the University of Havard and later with Luria (Christensen 2013)), which she transformed into economic capital (a donation from the Egmont foundation) to found the first Centre for Rehabilitation of Brain Injury. The new agents holding a heterodox position led to internal struggles for power with orthodox agents (Løvschal Nielsen 2004). An area of conflict was the different knowledge held by medicine and psychology of science. Specifically – new scientific knowledge challenging experiments and RCTs[8] by applying interpretative case study approaches for analysing underlying factors and behavioural disorders (Christensen et al. 1989). Luria and his colleagues’ well-known case study of a man with traumatic brain injury (TBI), *“The Man with a Shattered World”* (Luria 1972), is an example of a heterodox scientific study. Despite this, biomedical research standards functioned as a validation of the dominant actors and delayed the uptake of the new ideas. In a Bourdieuan understanding, this can be considered inertia contributing to consecration of doxa and the preservation of the hierarchy (Bourdieu and Passeron 1977).

A fusion of biomedical and psycho-social logic?

The institutionalization of NR with the seven treatment centers, the national knowledge center and the establishment of professional knowledge societies (e.g. DNS and DaNS) was a recognition of the new heterodox knowledge on brain injury. At the same time, this new knowledge represented a threat to the social order where the biomedical agents with its orthodoxy were dominant. This recognition also opened up for an increased number of professions to compete for a share of the rehabilitation practices, creating pressure from within NR (Hanssen and Sandvin 2003). These various practices and knowledge combined in NR can be viewed as – to some extent – a compromise between the orthodox and heterodox positions e.g. manifested in the white book based on the International Classification of Functioning, Disability and Health (ICF). NR opening up for multi- and interdisciplinarity can be viewed as a share of power between positions, and a change in focal point from the sick body to living a life with disabilities. This gradually opened up the closed doxa. Though the ICF, (in contrast to its predecessor ICIDH 2) claims to be a comprehensive framework, the ICF is still a tool for measurement and standardization, based on diagnosis and functioning (Bickenbach et al. 1999) in line with a biomedical approach. Therefore, the ICF may be viewed as a compromise of psychosocial and biomedical logic. Moreover, in documents published by the political social authorities, the biomedical doxa is still present in the discourse. This can be considered symbolic violence where biomedical logic is accepted by both neuropsychologists and social pedagogical agents: for example in referring to the biopsychosocial model of rehabilitation. Despite the opening up for psychological and pedagogical knowledge, NR is still a practice dominated by biomedicine. This inertia in the field can be connected to Bourdieu's concept of habitus (Bourdieu 1996b) providing us with an understanding of stability in the area since this is inherent in the material structures, in institutional structures and in the body as structures of perception and action. We could also argue in line with Hindhede and Larsen (2018) that relations between a number of sub-fields create a complex network that connects and stabilizes NR (subfields of institutions, subfields of professions, subfields of diseases, subfields of technology, etc.). Each of them operates with relative autonomy within a broader medical field, and as such they constitute a structural homology.

Biomedical domination – an alliance with the political field?

The political reform in 2007 can be viewed as a restructuring of professional services including de-specialization. It can however be argued that medicine regained its position in an alliance with the state after 2007 and that the biomedical domination is still present, although in a new representation. This is because biomedical standards and approaches are reflected in methods and terminology that are still applied in policy documents, as well as medical professionals being central actors and authors in creating these documents. To exemplify this, the Health Technology Assessment addressed the importance of evidenced-based medicine and practices, while maintaining that there was only weak to moderate evidence for neuropsychological programs (National Board of Health 2011). The actors behind the Disease Management Program are heavily represented by professional medical societies and hospitals. Therefore, a question arises as to whether the evidence-based practices of biomedicine re-established their dominant position in alliance with the health authorities through the increasing standardization and monitoring of the services. This alliance was driven by many different actors such as representatives of user organizations, health professionals and health authorities with an interest in standardized trajectories in order to enhance the quality and cohesion for all. This was done through public hearings and participating in the developmental work facilitated by the Danish Health Authorities.

It is possible to argue that there is collaboration between the left and the right hands of the state (Bourdieu 1998) due to the new alliance created between the medical professions, evidence-based medicine, and governmental monitoring. This is in line with Pinell and Jacobs' (2011) way of analyzing how biomedical dominance relates to 'other' areas outside medicine. We therefore state that despite an increased power of the professionals representing a psycho-social approaches as well as a strong state intervention in NR, it is still the medical profession that has the power to set the agenda in NR.

Relative autonomy – internal principles or external steering?

Bourdieu claims that an analysis of a field also involves positioning in relation to other fields (Bourdieu and Wacquant 1992). Inspired by *The field of cultural production in the field of power and in social space* (Bourdieu 1996a), figure 1 is an illustration of NR and its demarcation in relation to the surrounding fields in social space. In line with Bourdieu (1996a), this meta-figure is not based on statistical data (specific indicators of types and volumes of capital) but is a reflection of previous analysis, and hence a synthesis of capital possession of the primary agents and authorities as well as their involvement and success with setting the agenda also explicated throughout the analysis. In other words, the figure is considered a tool to illustrate graphically the interpretation of historical material.

The illustration shows that NR both prior to 1980 and after 2007 is considered a part of rehabilitation, constructed as a specialized subfield of the field of medicine and is also to an increasing extent framed by the political field (as can be seen in Figure 1, also simplified to include the field of economics). The movement of NR away from the field of medicine is explained by its opening up to humanities and social sciences, including psychology, pedagogy, therapy and social care, as well as interdisciplinary rehabilitation approaches (a combination of treatment, education, care, and work training). Today, NR has grown in size due to more patients surviving, technologies, clinical intervention possibilities, greater knowledge, and a higher political prioritizing, hence investment, in combination with the search for common principles (for example the white book) and common forms of organization (cf. the section of "the institutionalization of NR") (Gorski, 2013). The figure also shows that NR has moved from being relatively autonomous to more influenced by other fields (thus less autonomous), primarily due to the increased political and bureaucratic fields (steering on an organizational and practical level, such as through guidelines, legislation, etc.)

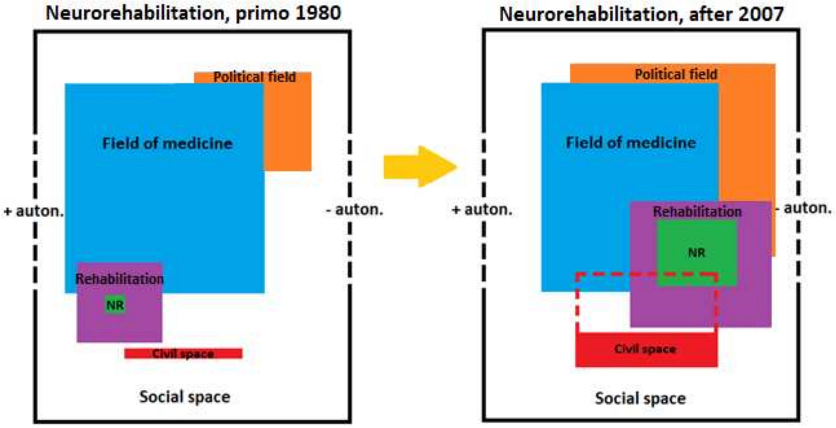


Figure 1: *The position of NR and its demarcation in relation to selected, surrounding fields, focusing on the relative autonomy of NR in the beginning of the 1980s and after 2007. The surrounding fields are constructed in terms of volume after the estimated influence on NR and the vertical line illustrates the hierarchy of dominance on NR.*

A turning point leading to changes in the structure and autonomy of NR occurred in 2007, due to a change of relational power with the allocation of increased authority to the municipalities. This political intervention challenged professional logics and weakened the relative autonomy of professions in NR. A consequence of the increased control of NR by the state was the increased use of technologies of governance: for example, the Disease Management Program (2011) from the political health authorities, which represented a new form of governance in which documents proposing knowledge recommendations for practices were published. The state thereby replaced the traditional governance of NR (primarily governing through structural changes) with a new form of governance at a distance, by applying political technologies (Rose 2009). This created an increased pressure from above (Hanssen and Sandvin 2003). Also, the audit report by the National Audit Office of Denmark (2016) examining ministerial duties, and concerning the strengthening of NR interventions can be viewed as a massive political steering of an area. A natural consequence of this increased political control has been a loss of relative autonomy, however, relative autonomy was also challenged by increased influence from other agents, such as civil actors. The term civil space unites patients and relatives, user organizations, as well as different forms of media. Civil space, as a ‘player’ has increased its authority due to changes in legislation, new trends, increased user involvement, cultural capital among the leading positions of the user organizations (convertible to symbolic capital in NR), and stronger organizations in general. This created a pressure from below (Hanssen and Sandvin 2003) which also challenged the relative autonomy of NR. To sum up, the increased domination especially from the political field from 2007 onwards but also from other fields/spaces such as e.g. the civil space entailed a reduced relative autonomy of NR.

This constructed and illustrative positioning of NR indicates that it is a subfield dragged in different directions and hereby constantly changing its structure (Bourdieu and Wacquant 1992).

Conclusion

This Bourdieu inspired field-analysis was approached by the categorizing of three constructed periods: *the genesis of NR* until the 1980s, where biomedical agents such as medical doctors struggled to conserve the orthodox position against a new heterodoxy (e.g. represented by professions such as neuropsychologists, pedagogues, speech therapists, special education teachers) breaking through due to central agents managing to convert their capitals to symbolic capital; *the institutionalization of NR* from around 1985-2007, where this heterodox knowledge was materialized in new specializations of rehabilitation practices, services, and institutions; and *the political restructuring of NR* in DK after 2007, characterized by increased and state dominated interventions. NR was transformed from being a relatively self-steering subfield with a biomedical doxa to being a heteronomous subfield characterized by psycho-social and comprehensive approaches also reflected in doxa. This makes NR a multi- and interdisciplinary practice characterized by heterogeneity, although with growing homogeneity in clinical practice due to an increased number of NR institutions, and later political guidelines entailing a formalization of treatments. Despite the increased power of psycho-social and comprehensive approaches, biomedical knowledge is still dominant and reflected in doxa. This is due to an alliance between the state and the medical agents both interested in standardized practices such as evidence-based medicine, and research methods based on bio-medical principles (e.g. RCT-studies). Furthermore, we have shown how external involvement has increased, especially with the local government reform in 2007 where the political (and economic) fields have increased their influence substantially, but also the field of civil agents (e.g. patients and user organizations) has increased their influence. This increased influence from external fields has reduced the relative autonomy of NR. This constructed outline of the history of NR in Denmark has shown that the subfield has a relatively short history with many interests and large transformations all contributing to complexity.

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Notes

[1] The Local Government Reform (also named the structural reform) is a political reorganization of the entire public sector in Denmark where the municipalities were reduced from 271 to 98 and five administrative entities at a level above the municipalities and below the central government of the public sector (regions) replacing the 15 counties.

[2] On the use of Bourdieu’s field concept in historical studies, see the relevant contributions in Gorski 2013.

[3] For further elaboration on the notion of subfields, please see Bourdieu 1996a, 120-24.

[4] An example of the knowledge center’s noteworthy contributions was the arranging of the first world conference on brain injuries in 1995 in cooperation with the International Brain Injury Association (IBIA) (IBIA 2019).

[5] VISO is an acronym for National Knowledge and Special Consulting Institution regarding social affairs and special needs education.

[6] DR1 is an independent public Danish TV Channel under the Ministry of Cultural Affairs fully financed through license fees.

[7] SATS-funding are yearly economic resources provided to chosen areas in the framing of vulnerable group of people decided by the political parties and canalized through a selected ministry. Despite of the economic capital investment this provides to an area it also witnesses a symbolic investment by expressing the relation of dominance in this subfield hence interventions and political responsibility of this group of people.

[8] Randomized control trial is a recognized and striving type of scientific (often biomedical) experiment which aims to reduce bias when testing a new treatment.

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http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf (accessed 20 July 2018)

Appendix I: Overview of references constructing the three periods

Time periodes	**Primary professional academic texts**	**Secondary sources**	**Primary political documents**	**Primary texts from homepages/medias**
Period I: The genesis of NR in DK	Christensen, 1984 Christensen, 2013 Goldstein, 1939 Kjærsgaard, 1993 Luria, 1972	Borg et al, 2011 Homskaya, 2001 Løvschal Nielsen, 2004 Teuber 1966	County Council, 1991 National Board of Health, 2011	
Period II: Institutionalization of NR	Angelsø and Smed, 1980 Christensen, 2013	Andersen, 2006 Bonfils and Bangshaab, 2012 Borg et al, 2011 Delica, 2007 Feiring, 2016 Froestad and Ravneberg, 1991 Gorski, 2013 Løvschal Nielsen, 2004 Schrøder and Schultz Petersen, 2012	County Council, 1991 Danish Health Authority, 1997 Danish Regions, 2011 Marselisborg center, 2004 Ministry of Social Affairs, 2006 National Board of Health, 2011 WHO, 2002	DANS, 2018 DNS, 2018 DR1, 2012 DUKH, 2018 IBIA, 2019 Vejle Fjord, 2018
Period III: Political restructuring of NR		Andersen, 2006 Bonfils and Bangshaab, 2012	National Board of Social Services, 2016h Danish Health Authority, 1997 National Board of Health, 2011 Danish Health Authority, 2011 Danish Regions, 2011 Ministry of Interior and Health, 2005	

Paper 2

Bystrup, M. R. & Hindhede, A. L. (2019). Conversion of Social Capital in the Rehabilitation Process of Adolescents Following an Acquired Brain Injury. In *New Dynamics of Disability and Rehabilitation* (pp. 195-223). Palgrave Macmillan. **https://doi.org/10.1007/978-981-13-7346-6_9**

9

Conversion of Social Capital in the Rehabilitation Process of Adolescents Following an Acquired Brain Injury

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9.1 Introduction

The Danish welfare state is often considered to be a prototypical social democratic, universal welfare system (Esping-Andersen 1990). This is true for the allocation of health services, including treatment and rehabilitation, which are free of charge for all, regardless of income (Ministry of Health 2016). However, health inequalities in Denmark among different socioeconomic groups are large and growing (Diderichsen et al.

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I. Harsløf et al. (eds.), *New Dynamics of Disability and Rehabilitation*,
https://doi.org/10.1007/978-981-13-7346-6_9

2011). These inequalities concern not only the uneven distribution of illness but also socioeconomic differences in the outcome of treatment/rehabilitation in terms of survival, dependence on care, and quality of life (Andersen et al. 2014; Geckler and Hansen 2014).

This unevenness of outcomes regarding treatment and rehabilitation also seems to be closely related to the patient's family, despite Scandinavian healthcare services in theory being largely independent of interventions by relatives (Geckler and Hansen 2014; National Board of Health 2011). On the other hand, it is becoming an increasing political priority to involve relatives in the decision-making and rehabilitation processes within the Danish healthcare system, with one of the arguments for this change being the reduction of inequality (Ministry of Health and Prevention 2014). The supposition is that, if socioeconomically advantaged patients and relatives have the tools and framework to be more active and take on more responsibility, healthcare resources can be allocated to patients with more need. Generally, prior studies have shown that the involvement of relatives is connected to better rehabilitation outcomes for individuals with a traumatic brain injury (Foster et al. 2012), and that severe brain injury strongly increases the patient's dependence on others (Doser et al. 2018). Yet, to date, little attention has been paid to the rehabilitation courses of those with the most severe brain injuries (National Board of Health 2011).

Adolescents—already a potentially vulnerable group because of the many life changes and challenging situations they encounter over a short period of time—may suffer increased damage to their emotional and social lives, as well as their physical and cognitive abilities, when they acquire a severe brain injury (Doser et al. 2018). Support from family for children and young people may therefore be particularly significant in terms of a successful rehabilitation and return to their lives thereafter (Gan et al. 2006; Sander et al. 2002). However, 'family' is not a fixed entity, and varies in size, constitution, quality, and the way its resources can be converted into rehabilitative assets (Guldager et al. 2018; Norup 2012). In other words, the levels of resources that families possess and are able to mobilize are valued differently among health professionals within the rehabilitation system. Despite our knowledge of the existing inequalities in the Danish healthcare sector, we know little about how to approach and handle diagnosis, treatment, and rehabilitation for different social groups (Kamper-Jørgensen and Rasmussen 2008). In addition, most previous research on relatives concerns spouses;

there is less focus on parents, and even less still on siblings (National Board of Health 2011). Thus, there is a dearth of studies that seek to comprehend the capitalization and cultivation of assets among families alongside the variations in the outcomes of rehabilitation processes, and thus on the role that these assets play in health inequality.

In this chapter, we investigate how intangible, non-material assets in the form of the family connections of the relatives of young people with an acquired brain injury are invested and converted to services and 'goods' during the process of rehabilitation. We show that some families understand the health system better than others and therefore reap greater benefits through their networks in terms of advantage, preferential treatment, or additional rehabilitation services from the welfare state. The set of resources that accrue to the families through their social relationships is a form of social capital that facilitates the attainment of goals. Moreover, social relations only turn into capital when that so-called 'social capital' is valued. According to Portes (1998), these unequal possibilities of conversion help to explain some of the asymmetries in benefits gained by two actors in a relationship. Our study therefore contributes to the establishment of a theoretical context for the empirical investigation and explanation of the impact of social capital by asking: How are forms of social capital invested and converted by the relatives of young people with a severe acquired brain injury during the rehabilitation process?

9.2 Social Class and Social Capital in the Context of Neurorehabilitation

Although the origins of the notion of social capital lie in the nineteenth-century classics of sociology, the most influential contemporary manifestations of the concept seem to be Bourdieu (1986), Coleman (1988), and Putnam (1993). In his renowned paper on the origin and application of social capital in modern sociology, Portes (1998) drew parallels with Bourdieu and Coleman's earlier conceptualizations and theories. He argued that social capital can be considered (a) a source of social control generated in closed networks, where the potential for social control is highest; (b) a source of family-mediated resources; and (c) a source of resources mediated by non-familial networks. According to Portes, the first of these aspects follows on from Coleman's usage of the term 'closure', the second partly intersects with what Bourdieu considers 'cultural capital', and the third aspect comes close to Bourdieu's understanding of social capital. We consider these three sources to be productive in the investigation of social capital in the context of neurorehabilitation.

Bourdieu and Coleman's theories were developed more or less at the same time, and both focus on the existence of several forms of capital and on the transformation and outcome of both economic and non-economic resources. However, they also differ in several ways. Bourdieu's conceptualization of social capital is part of his broader theory of fields, which also addresses power and structural inequalities. Capital, according to Bourdieu, is a resource that solely exists and functions in relation to specific fields, and these fields operate according to their own internal logics and dynamics (Bourdieu and Wacquant 1992). For Bourdieu, social capital is the sum of the resources that accrue to an individual (or a group) by virtue of being enmeshed in 'a durable network of more or less institutionalized relationships of tacit acquaintance and recognition—or, in other words, to membership in a group' (Bourdieu 1986, p. 248). Bourdieu's interest in (social) capital primarily concerns the constant struggle for domination existing among the positions in a field. Hence, the accumulation of social capital can be considered a strategy of investment in order to strengthen one's position:

> The volume of the social capital possessed by a given agent thus depends on the size of the network he can effectively *mobilize* and on the volume of the capital (economic, cultural, or symbolic) possessed in his own right by each of those to whom he is connected. (Bourdieu 1986, p. 249; our emphasis)

Each field can be understood to have a specific doxa in the understanding of its own logic and common beliefs, its own forms of social control, its own structures of opportunity, and specific types of resources. In this study, the field we relate to is the Scandinavian field of (neuro)rehabilitation, which is considered a multidisciplinary subfield, though it is dominated by the medical field, in alliance with the political field (Carlhed 2007; Feiring and Solvang 2013; Sandholm Larsen and Larsen 2008).

Cultural capital exists in three forms: embodied (dispositions), objectified (cultural goods), and institutionalized (educational qualifications)

(Bourdieu 1986). For Bourdieu, the social capital of the family also encompasses cultural capital in the form of involvement in cultural practices and possession of cultural goods, as these may facilitate children's access to, for example, education. However, Bourdieu's concept of social capital 'does not lend itself either to a precise definition or a close empirical assessment' (Hindhede 2016, p. 539), nor does he explicitly discuss forms of social capital. Following Bourdieu, we stress the importance of considering social capital as both an actual and a potential resource. By 'actual', we mean that the resources are capitalizable or interchangeable in the here and now. 'Potential' social capital, on the other hand, reflects long-term strategies that include the cultivation of networks that might be useful in an unforeseen situation. As Bourdieu (1980, p. 2; our translation) explained, what characterizes groups of individuals that possess social capital is that they 'are not only endowed with common properties (likely to be perceived by the observer, by others, or by themselves), but are also united by permanent and useful relationships'.

Meanwhile, Coleman's theory of social capital combines rational choice theory and structuralism. He defines social capital as consisting of any social and structural features that are useful to individuals for specific actions. A central difference between Bourdieu and Coleman is the latter's focus on 'closure' in social relations, constituted by the relations between parents and children or other close members of the family (Coleman 1988). When families are more connected to one another, trust, norms, and effective sanctions from parents are more likely, and parents can therefore more effectively enforce their interests. The strength of the relation between these family members is a measure of the strength of social capital. This delimitation of the outside world is necessary in order for the relation to constitute social capital. Coleman (1988) claimed that social capital in the family can create human capital, such as when the parents are involved in the lives of their children. Portes's (2000) testing of social capital, in his study on the educational attainment of immigrant children, stressed that such factors as both biological parents being present, parental involvement, network closure, and socioeconomic status were criteria for estimating social capital effects. Norms, trust, authority, and so on also constitute solidifying forces of social capital that facilitate certain actions while constraining others (Coleman 1988). As Coleman (1990, p. 243) stated, 'a norm concerning a specific action exists when the socially defined right to control the action is held not by the actor but by others'. In everyday life, the right of control is informal and diffuse; it extends to almost everyone considered to be a competent social actor. However, Coleman disregarded the structural elements of social capital. Moreover, his framework obscures the relations among the formation, distribution, and operation of social capital as both an action and a process, while, as set forth by Portes (1998, p. 5), 'equating social capital with the resources acquired through it can easily lead to tautological statements.'

A network approach to researching social capital, such as 'social network analysis', aims to overcome the limitations of both Coleman and Bourdieu by examining in more detail the actors in a network and the ties between them. Social network analysis has its focus in the structure, function, and composition of the network ties surrounding the individual. The current chapter is inspired by this theoretical and methodological thinking, in order to better understand the kinds of network connections families draw upon in rehabilitation processes. According to Borgatti et al. (2013, p. 7), network theorizing is based on a view of ties as 'conduits through which things flow – material goods, ideas, instructions, diseases, and so on'. Thus, social network analysis is based on the assumption that the behaviours, attitudes, and values of individuals are shaped through contact and interaction with others. Interpersonal ties most often come in three versions: strong, weak, and absent ties (Granovetter 1973). Strong ties typically are among individuals characterized by emotional intimacy, intensity, and trust; weak ties are non-frequent and transitory relations; and absent ties are instances when you might expect a tie but it does not exist, such as in a group of friends in which two members are still distant from each another (Montgomery 1994).

Social networks are typically illustrated as graphs with two sets of data: (1) actors and (2) the ties connecting the actors. We are interested in the structure, function and composition of personal network ties which is called the egocentric network. This type of network consists of all the alters around the ego(s) who can be considered as providing resources (family and other relatives, friends, healthcare professionals, social workers, etc.). Our focus is on the nature of the ties connecting the egos and the alters, as well as the characteristics of the alters (Borgatti et al. 2013, p. 262). Taken together, these approaches contribute to answering our research question.

9.3 Methods

The relatives of eight young people (aged 15–30) with a severe acquired brain injury[1] represent the focal point of this study. In order to empirically investigate how relatives invest their social capital and convert it into rehabilitative goods, a triangular and longitudinal study design was adopted, comprising direct observations of hospital discharge meetings, focus group interviews with relatives six months after discharge, questionnaires answered by each of the closest relatives, and medical records from the rehabilitation hospital where the young people were treated. The principal eight cases were supplemented with interviews with an additional six families of young people (also between 15 and 30 years old) with an acquired brain injury of a different severity. These additional families were interviewed at various times after hospitalization (in contrast to the eight original interviews, which all took place six months after the hospital stay), varying from six months to two and a half years after hospitalization. Altogether, the families of eight young boys and six young girls are represented in this study. The gender mix, with a predominance of males, approximates with general patterns in the study population (Corrigan et al. 2010). Twelve of the participants were ethnic Danes and two had a different ethnic background. All of the young people were recruited at one of the two specialized rehabilitation hospitals for patients with severe brain injuries in Denmark.

The data were analysed using a deductive approach revolving around the theoretical frameworks of Bourdieu and Coleman. We used NVivo (version 11; QSR International) qualitative data analysis software to assist in obtaining an overview and coding the data. The families were given

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[1] In neurorehabilitation, an acquired brain injury is often classified into one of three categories: mild, moderate, or severe. One set of criteria is that of the National Board of Health's (2011) categorization, which is based on the number of days of hospitalization, wherein more than 28 days is considered 'severe'.

both verbal and written information regarding the study before we obtained their informed consent for participation. The identities of the families have been anonymized and pseudonyms used in the reported findings. The study received approval from the Danish Data Protection Agency and the data were handled according to its requirements.

9.3.1 Observations

The discharge meeting at the rehabilitation hospital is considered a crucial juncture during the rehabilitation process because important decisions are made concerning the rehabilitation course after hospitalization and through life thereafter. At the discharge meeting, many actors (including various professionals from the rehabilitation hospital, the municipality, and, in some cases, a residential rehabilitation institution, as well as relatives and sometimes the patient themselves) are brought together. In six out of the eight cases in our study, a discharge meeting was held and observed. The meetings were offered to patients living in a specific Danish region, or when the patient was under the age of 18. In two cases, the meetings were conducted via video conferencing, with the municipality representatives participating online. The number of participants varied from 10 to 16. Nonparticipant observation was adopted by the first author (MRB), with acceptance from the participants of the meeting. Theory-based observational field notes were written on the basis of a constructed observational guide, with a focus on the positioning of the relatives, their adopted roles, and negotiable topics. The meetings were recorded digitally and transcribed verbatim.

9.3.2 Interviews

Focus group interviews with the eight principal families and four additional families were conducted by MRB (in total, 33 relatives; 25 plus an additional eight relatives). The relatives were parents (or step-parents) and, in most cases, siblings; the young people themselves were not present. The families (primarily, the parents) themselves decided who would be defined as the closest relatives and participate in the interviews. The families were all interviewed in their own homes, in an attempt to minimize the asymmetry of power as well as to use their physical framing as an empirical observation. The interviews were digitally recorded and transcribed verbatim. A semi-structured interview guide was constructed, based on Bourdieu's concepts of capital (1980, 1986), to explore the families' experience of the rehabilitation process and their life situation, in order to reveal resources and strategies.

9.3.3 Questionnaires

We used a questionnaire constructed with inspiration from Fischer (1982) and Alexander (2009) to map the families' personal network. The questionnaire was answered by the relatives during the in-depth interview session. The questionnaire included questions on income, education, occupation, and co-habitation. Using this information we classified each family according to Olsen et al.'s (2012) social classes in the Denmark categorization scheme. This categorization contains a five-factor social class index, as follows: 'upper class' (1% of the Danish population), 'upper-middle class' (9%), 'middle class' (24%), 'working class' (47%), and 'underclass' (20%). Our study featured two families representing the middle class, three families belonging to the working class, and three families identified as underclass. In addition, the questionnaires contained questions to generate egocentric networks of the relatives corresponding to both before and after the young person's injury (Bidart and Charbonneau 2011). From this questionnaire, we analysed the different attributes of the relationships between ego and the various alters. We looked at the *quality* of the relationship, that is, how often they are in touch (as indicated in the diagrams by the thickness of the arrow), *reciprocity* of the relationship between the egos (indicated by the arrows being one or two way), as well as its *nature* in terms of being family, friend, boy-/girlfriend, partner, or involving a welfare professional as alter (e.g., a social worker), and so on (as indicated by different colours of the circles). The ego (the relative who has answered the questionnaire) is placed in a square-like figure in contrast to the alters placed in circles).

The green contours are placed in order to show who constitute the family core estimated on the professionals' (medical) journals as well as interviews with the families.

9.3.4 Medical Records

Medical records from the rehabilitation hospital for each of the young persons constituted supplementary empirical material pertaining to the description and timeline of the rehabilitation process.

9.4 Findings

9.4.1 Network Structures and Resources in the Rehabilitation Process

Among the families of the young people, three structures were identified, which involved various levels of closure: (1) a split family structure; (2) a strong, closed family structure; and (3) a small and weak family structure. These family structures were related to the family's social positioning in society.

9.4.1.1 A Split Family Structure

This family structure is considered to feature only a little cohesion, as its members are not well connected because there are few to no single ties between family members, and, in some cases, there is conflict in the relations between some of the closest family members (e.g., between the biological parents), or because there is a wide opening up of the non-familial network that thereby has precluded it being a strong, closed (family) unit. This lack of cohesion hinders both trustworthiness and trust building, which, according to Coleman (1988, p. 101), is crucial for a family's ability to mobilize social capital: 'A group within which there is extensive trustworthiness and extensive trust is able to accomplish much more than a comparable group without that trustworthiness and trust'.

In our study, the case of 'Agnes' is an example of a working-class family that is in conflict. Agnes is a woman in her late 20s who acquired a severe traumatic brain injury in a vehicle accident involving her boyfriend, after which she experienced strong interactional limitations. The internal conflicts among Agnes's family members hinders family closure and prevents them from mobilizing social capital to use as leverage towards a better rehabilitation process. Agnes's mother, stepfather, maternal aunt, and the husband of the maternal aunt attended the discharge meeting. The maternal aunt had, for a period of time before the injury, served as the official contact person for Agnes, and thus was positioned close to her. Half a year later, when Agnes's mother, stepfather, and siblings were interviewed, it was revealed that the family was in conflict with the maternal aunt, and they were suing each other due to conflicts concerning guardianship and choice of rehabilitation institution among other issues:

> SIBLING: We do not really talk to her [maternal aunt] because she wants parental jurisdiction over Agnes – or … what is it called? That's litigation you are in process with, aren't you?
>
> MOTHER'S HUSBAND: No, she wants guardianship.
>
> MOTHER: She [the maternal aunt] got angry at the time when I got guardianship of Agnes.
>
> INTERVIEWER: Because …? Why did she get angry about it?
>
> MOTHER'S HUSBAND: Because the problem was that it became a [nursing home].
>
> MOTHER: Because I chose she was at [nursing home], and my sibling became very angry and said it was the worst place I could place my [child]

In addition, the family was in a custody battle with the father of one of Agnes's children. Network analysis established that the family was split both before and after the injury. Notably, Agnes was not mentioned by any of the family members as a relation during the answering of the questionnaires, either before or after the injury. This could be an oversight or explained by the severity of the brain injury leaving Agnes with very limited interactional possibilities, which might be why she is not considered a relation, but it could also be an indication of the family not being close. They have a significant geographical distance between them (the mother moved several hours' drive away from her children because of her new husband). Medical records also indicate that the mother disapproves of Agnes's boyfriend, and therefore the tie between them was already weak before the incident. Through the in-depth interview, we found that the relationship between the mother and her injured child was reduced to a visit once a month, while the siblings had only seen her a couple of times at the care home. One of the siblings participating in the interview declined to answer the questionnaire. In addition, the younger sibling left the interview in tears before its completion and therefore did not answer the questionnaire either. No one followed her, but the mother asked the brother's new girlfriend (who had no relationship with the younger sibling) if she would go and console her. The younger sibling lives several hours away from her mother and close to an hour's drive from her siblings, and was not mentioned as a relation by any of them either. Neither the mother nor the stepfather mentioned any of the children as a relation. The relation between the mother and the stepfather exists, according to the questionnaires (see the network mapping in Fig. 9.1); however, the in-depth interview suggests that the emotional relationship and support provided by the stepfather is limited. For example, he commented, 'It is, at any rate, a daily challenge that she [mother] feels so bound by [Agnes and her situation] and cannot let go of it', and showed a lack of understanding of the mother's need to keep her hopes up and stay near the phone in case of an urgent call from the nursing home. Agnes ended up in a discontinued rehabilitation process (e.g., in-between periods with no rehabilitation, and uncertainty regarding the next step in the process) and at a care home with elderly residents that offered no expertise in neurorehabilitation, despite the possible rehabilitation possibilities expressed by hospital professionals at the discharge meeting.

9.4.1.2 A Strong, Closed Family Structure

This family structure was identified in various sizes, and it is characterized by a strong and relatively closed core, consisting, at the very least, of both biological parents, both before the injury and six months following the

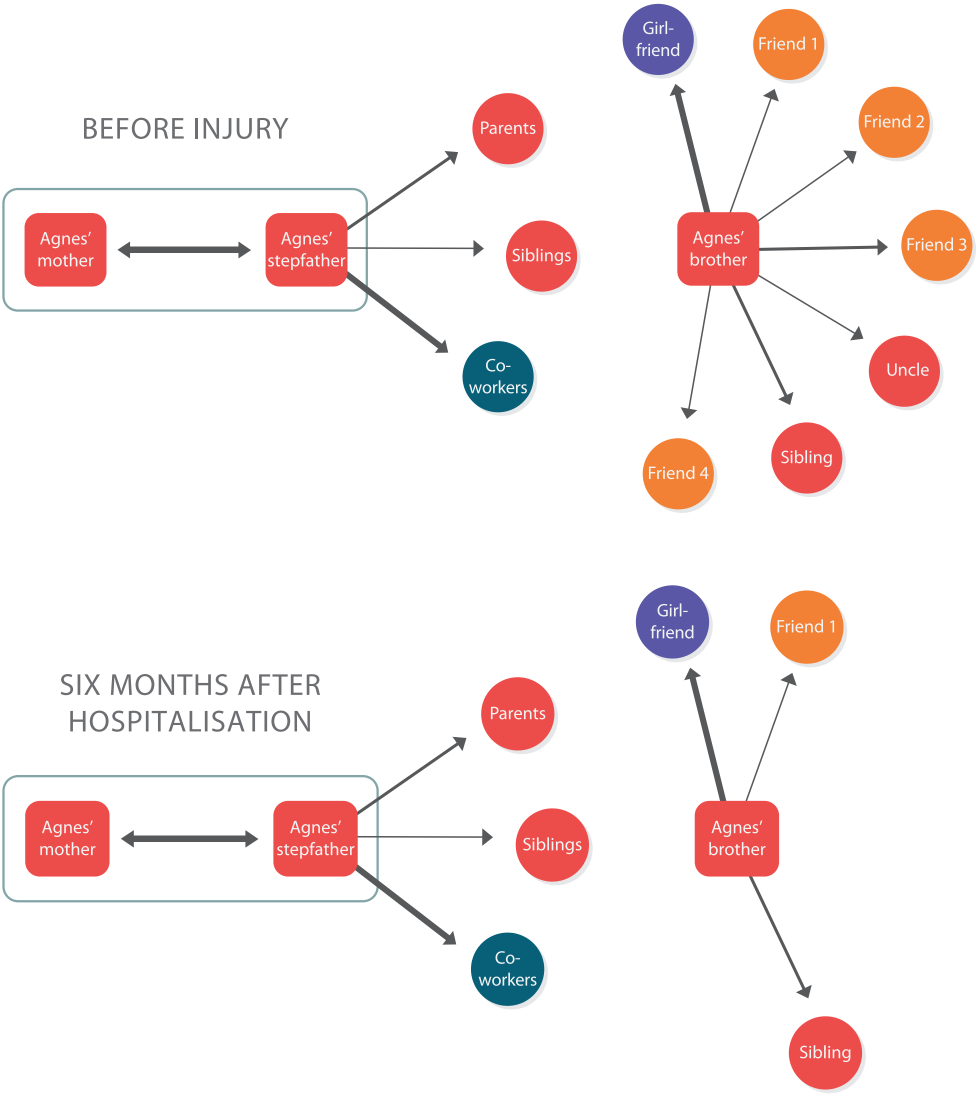

Fig. 9.1 Network maps of a split family structure, exemplified by the relatives of 'Agnes' before the injury and six months after her discharge from the rehabilitation hospital. The 'family core' is marked with a green contour

individual's discharge from the rehabilitation hospital. These families had strong, supportive involvement in each other's lives and in the rehabilitation process of the young patient, and formed strong connections to the professionals that worked with their children. Notably, these families mentioned the injured family member as a relation regardless of the severity of the brain injury. This might be a sign of a preserved family closeness including the young injured person despite the brain injury as well as the complex life situation this has entailed for the family.

An example of this family structure is the case of 'Smilla', who comes from a middle-class family. She is younger than 20 and acquired her brain injury in a vehicle accident also involving another close family member. During the interview, the family mentioned in various ways that the four of them are closely connected, and also that, prior to the accident, family closeness was always highly prioritized and appreciated. These expressions were supported by the findings from the network analysis, which demonstrates that, while the families' networks are reduced, the family core and closeness remain intact (see Fig. 9.2). Smilla's mother expresses in this regard the need they felt for family closure when the crisis struck them:

> SMILLA'S MOTHER: You are so much in a crisis and you do not have the need to communicate anything to anyone. It might sound crazy, but the care from others is completely indifferent, because you close yourself up in a closed unit [comprising the four family members], where you only focus on what is essential – it's your child's life.

This is despite the fact that, as Smilla's sibling explains, the family closure is challenged by the many professionals constantly surrounding the family:

> SMILLA'S SIBLING: Now, there are all kinds of people around us all the time. I think that it's problematic. I don't need to be anything for you or any of them at [residential rehabilitation institution], but, on the other hand, I should. It is not like being the three of us [living at home] or together with Smilla.

Despite the challenges to family closure, they remain a strong unit, meaning they have advantages with regard to the rehabilitation process, such as an extended period with compensation for loss of earnings and psychotherapeutic treatment granted for the whole family, as well as other benefits mentioned in the following sections.

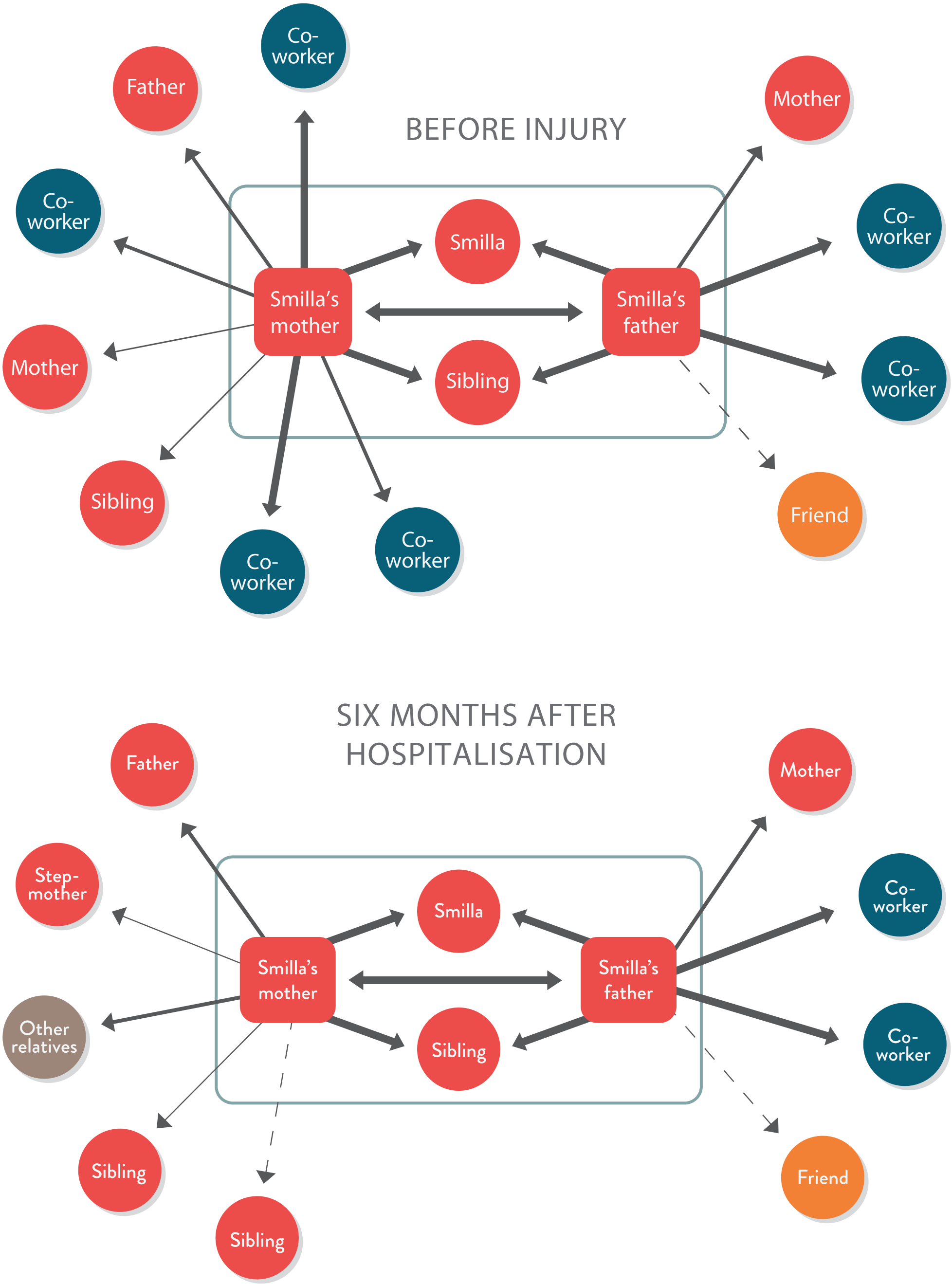

Fig. 9.2 Network maps of a strong, closed family structure, exemplified by the relatives of 'Smilla' before the injury and six months after the rehabilitation hospital. The 'family core' is marked using a green contour

9.4.1.3 A Small and Weak Family Structure

This family structure was found to consist of only a few relations close to the young person, and involved persons who were in relatively vulnerable life situations themselves (e.g., because of their own illness, few socioeconomic resources, ethnicity, living in deprived areas, few close relatives). This family structure is the one least involved in the rehabilitation process of the young person (e.g., few visits, little familiarity between the family and the professionals), and is characterized by frustrated, powerless, passive, and/or despairing family members not making demands for rehabilitation services.

An illustration of this structure is the case of 'Rasmus', a young man who, in his late 20s, acquired a severe traumatic brain injury through a vehicle accident. He stayed at a rehabilitation hospital and, at the time of inclusion in this study, was being considered for rehospitalization almost three years after the injury because he had shown signs of development at the care home in which he was institutionalized. Rasmus comes from an underclass family. He has an older sibling with renewable disability. In other words, his parents have been in a vulnerable situation far longer than the parents of the other young people included in the study. This fact may help explain their limited numbers of social relations, as sustaining friendships takes effort and work. This already vulnerable situation may also be part of the explanation for why their conception of their network (as inferred through the questionnaires) was exactly the same before as it was after the injury. Notably, they did not mention each other as relations, thus reflecting a structure of only weak or almost absent ties (see Fig. 9.3). This could be an oversight, since they live together, visit Rasmus together, and so on. On the other hand, it could also be the case that the parents do not consider each other as a relation worthy of mentioning, as the interview was characterized by a defeated and strained atmosphere and an attitude of blame between them. The mother also expressed that she didn't share her innermost emotions:

> MOTHER: It is not all we let out to each other. No, it is not … issues that come very close. It isn't all you're told [*directed to her husband*]. You should not believe that.

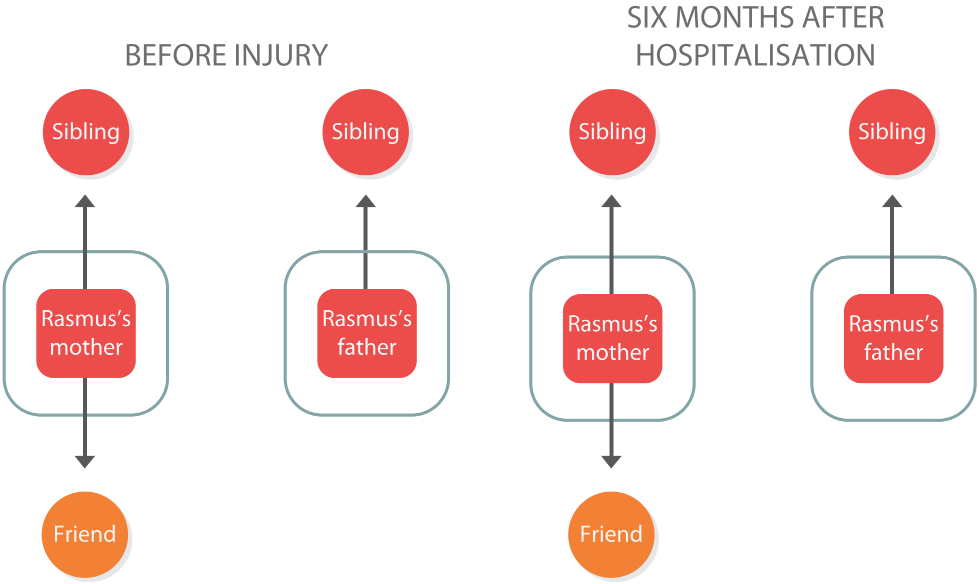

Fig. 9.3 Network maps of a small and weak family structure, exemplified by the relatives of 'Rasmus' before the injury and six months after the rehabilitation hospital. The 'family cores' are marked with green contours

These family structures are characterized by making no or few demands on rehabilitation services and tacitly accepting what they were offered—for example, regarding where the young family member was placed. This was even the case when one of the young persons was evicted from a residential rehabilitation institution and was returned home without any rehabilitation.

9.4.2 Sources of Family-Mediated Resources

Family-mediated resources are, according to Portes (2000), in line with Bourdieu's concept of cultural capital, in that a family facilitates their children's access to, for example, education and transmits a set of values and outlooks, variously classified as 'low-' to 'high-brow' culture. Here, we draw on Bourdieu's ideas of cultural capital in the form of involvement in cultural practices and the possession of cultural goods. In the case of rehabilitation, the 'goods' strived for are scarce healthcare services, such as longer stays at the rehabilitation hospital and residential rehabilitation institutions, stays at specific, preferable residential rehabilitation institutions, compensation for loss of earnings, psychotherapeutic treatment, and facilities/devices to improve the patient's everyday life (e.g., a large iPad for improving communication, reconstruction in the home to make space for a wheelchair, etc.). In the empirical material, different strategies to invest in the cultural capital of families in order to enhance their situation have been identified, which shows how the relatives in various ways (and to various extents) understood the doxa and used it actively in their strategies (Bourdieu and Wacquant 1992). These strategies include a willingness to cooperate, showing the rehabilitation potential of the injured individual, mobilizing various forms of power to use as threats, and confronting professionals with their mistakes.

An example of using threats is seen in the case of 'William', who is in his early 20s and acquired a brain injury because of a work accident. William is from a working-class family. His mother was dissatisfied with the rehabilitation services and therefore wanted to put pressure on the municipality to induce them to provide better services. She used knowledge gained from her work with another vulnerable group of people, as well as her understanding of how to use the media (attained through a contact of another relative, who, in cooperation with a TV station, was producing a documentary film), to bring attention to this issue:

> MOTHER: I also know what [the municipality] like and what they dislike. If I take it one step further, for example, to the city councillor, or if I tell [the municipal coordinator of brain injuries] that 'this is not a threat, but the next step will be contacting the media' … [William] only gets one chance… So, I know [because of her work] which buttons to press …
>
> INTERVIEWER: Do you have any contacts with the media, or which strategy do you choose?
>
> MOTHER: You have probably read about [name of female], her from [a television programme about a person acquiring a brain injury and his wife and the subsequent life implications] … I correspond quite a lot with her on Facebook in closed messages … and she says, 'You shouldn't doubt, you call [TV channel] and then they'll tell your story'.

As shown here, the mother uses her knowledge as a strategy with which to obtain better rehabilitation services, by threatening to go to the city councillor or contacting the media.

In the case of Smilla, the parents' involvement in the rehabilitation process seems to be an advantage because it has taught them the 'game', consisting of a special preoccupation with the physical body in the process of rehabilitation, a shortage of professional time and 'hands', and the necessity to show rehabilitation readiness and improvement and respond to this by showing willingness to invest their own time, energy, and acquired knowledge. This is demonstrated in the quote below, expressed by the mother during the discharge meeting:

> SMILLA'S MOTHER: We [parents] take part in all this work with Smilla. She is very confident with us doing the things and we know Smilla's body just as well as [the physiotherapist] … and do things the same way. And we keep a close eye on what the professionals do … to be able to do as much as possible, because we know that there are only limited resources to work with Smilla, and therefore it is very important that someone can take over when the professionals let go. And this is still the case when Smilla is at [residential rehabilitation institution]. So, the time we spend with Smilla will be used with the focus on training in our being together, and we will continue doing so, because she benefits a lot from that.

9.4.3 Sources Related to Non-familial Network

According to Portes (2000), social capital viewed as a non-familial network constitutes what Bourdieu conceptualizes as social capital—that is, a *potential* resource in which a family may or may not invest. The magnitude of the possible network to become an object of investment varies among the families. However, due to the service-intensive Danish welfare state, family members will always have at least an external network of professional support. In the empirical cases, three primary forms of non-familial network were identified and activated by the families: (1) a network of known relations (friends, family, neighbours, and colleagues),

(2) a professional network, and (3) a network of tacit and peripheral acquaintances. These will be explained in more detail below.

9.4.3.1 A Network of Known Relations

The data show that the networks vary with regard to the types of relations prompted, the kind of support they contribute, and in which situations and stages of the rehabilitation process the network is valued and becomes an object of investment. The largest and most immediate provided network was that of 'Christian', a young man (less than 20 years old) living in a small village with a large group of friends. Immediately after the vehicle accident that inflicted the brain injury, many of his friends made the long drive to the hospital to offer their compassion and support. Furthermore, the entire group of friends offered their help to the family. During the interview with the family, Christian's older sibling noted, 'When the accident happened, they [Christian's friends] all dropped everything and drove to the hospital [several hours' drive from home], and suddenly 20 people show up.' A year after the accident, the group of friends were still supportive of the whole family, and were helping to prepare for Christian's return home after a stay at a residential rehabilitation institution. The whole year, they had offered practical and emotional support, and, to some extent, also financial and counselling support to the family. An example of this support is when the group of friends took over the housework in the family home while the parents were at the hospital, including taking responsibility for the younger sibling (cooking, sleeping over, preparing packed lunches, bringing her to school, driving her to leisure activities, etc.). The year when Christian was being rehabilitated several hours away from their home, they visited him once a week and contributed by picking him up and returning him for the weekends. Also, they contributed with emotional support to the family. As the older sibling confirmed:

> CHRISTIAN'S SIBLING: Well, I can say that I couldn't have done it without [the support]. Without the boys. Without his friends. I couldn't have in any way. They helped with the little [sibling] every day, they helped with

> the food; well, they were just there for me, whether it was a hug or to go for a drive or whatever the hell was needed.

9.4.3.2 A Professional Network

When a person acquires a brain injury and is hospitalized, the Danish welfare state allocates more or less automatically and free of charge the services of professionals. Nonetheless, despite ideals of equal access, our observations during the discharge meetings revealed that families' familiarity with the professionals varies, as does the extent of professional services as a source of information and resources provided. The number of resources and professionals are limited, meaning that some families profit more than others. This inequality in gaining benefits is captured by Portes (1998, p. 15) in the observation that 'the same strong ties that bring benefits to members of a group commonly enable them to bar others from access'. Our empirical findings show that it is predominantly the families with a strong, closed family structure that draw on the professional network as a resource to the greatest extent.

An example of a professional source of social capital provided by the state can be seen in the case of Smilla, who was hospitalized for ten months with her mother co-hospitalized with her during the week and her father on weekends. This situation contributed to the strong ties between the family and the professionals at the rehabilitation hospital. In addition, they had a certain amount of familiarity with one of the representatives from the municipality over a long period (approximately four years), due to their child's mental illness. This familiarity, and hence the provision of as well as appreciation for the professional network as a resource, was apparent at the discharge meeting in several ways. The father expressed, with humour, 'Unfortunately, we have for quite some years known how good you are.' A reciprocal appreciation was also expressed by the professionals from the residential rehabilitation institution and the rehabilitation hospital—for example, while talking about Smilla's transfer to the new institution: 'There is no doubt that this [the parents] is also a resource for us, that somebody comes who knows her that well.' Likewise, the physiotherapist (at the rehabilitation hospital) added, 'It is a HUGE help.' The familiarity was expressed by the mother, contributing with small details during the description of the treatment and revealing that she has been closely involved in Smilla's everyday rehabilitation and has almost served as a colleague. It was also apparent that the mother had consulted the municipality, the professionals at the residential rehabilitation institution, and the chairman of the discharge meeting ahead of the meeting, regarding topics to be discussed. This was revealed, for example, when the chairman at the end of the meeting said, 'I believe this was pretty much what we had been talking about … [*directed at mother*]?' This familiarity and appreciative relationship between the family and professionals was reflected in a good atmosphere at the discharge meeting, where everyone present showed a willingness to sacrifice a little extra to provide the best for Smilla, including extra professional resources, for example, in the transition from the rehabilitation hospital to the residential rehabilitation institution:

> MEDICAL SOCIAL WORKER: Then we can hear from the residential rehabilitation institution what they think about that task [rehabilitation of Smilla].
>
> HEAD OF DEPARTMENT, RESIDENTIAL REHABILITATION INSTITUTION: We have been attentive on the sideline and had your [family] visit; unfortunately, I was not working that day, but, when I consider the things you're talking about, we can easily continue that. But, we really want to send two of our employees to meet [Smilla] here [at the rehabilitation hospital] at the beginning of September.

Taken together, these efforts create both tangible and intangible advantages, such as smoothness in the rehabilitation process, where the next step of the rehabilitation process is planned ahead of time because the agreements have been made and the institutions and professionals are well prepared. Another example of this extra willingness is evident in the following further extract:

> SOCIAL WORKER, MUNICIPALITY: As a rule, full lost earnings wouldn't be granted to the mother when the child is being placed or when a young person is being placed, but this is a special situation [because of Smilla's

> mental illness], so what [the management group] actually decided is a month to one and a half months, where you [mother] have a period of time to accompany Smilla [starting up at the residential rehabilitation institution].

9.4.3.3 A Network of Tacit and Peripheral Acquaintances

Portes (1998, p. 7) stated that, 'To possess social capital, a person must be related to others, and it is those others, not himself, who are the actual source of his or her advantage.' He argued that, in general, immigrant families compensate for the absence of the form of resource embedded in outside networks and instead capitalize on the second source of social capital: familial support. The case of 'Ahmad', who is a young man (less than 20 years old), offers an example of an immigrant family comprising a network with sources of capital only for a limited time and a form of capital that is not convertible to rehabilitation services. Ahmad lives with his chronically ill mother on social welfare, with an absent father living abroad. The two of them live in a deprived area with a significant number of people on welfare. He has two older siblings living in different regions of the country, where they are occupied with work and education. The family is categorized as belonging to the underclass. The network map of the mother shows a small network outside the four of them: the mother has only two friends, and, apart from them, has experienced social isolation since the return of her child, as she described in the interview:

> AHMAD'S MOTHER: When Ahmad came home, I didn't dare to go out. I took care of him the whole time. That is a natural thing that a mother should … my son has been in an accident and is at home the whole time, and not going out. What should I do if I go outside, if something suddenly happens?

The reduced physical network in their daily life is, however, compensated for by a huge network provided virtually. The sibling explains how, in the religious milieu of which they are a part, people are there for one another in case of emergency. The sharing of Ahmad's situation on social media provided a huge number of network members, compensating for the vulnerability of the family:

> Ahmad's sibling: Of course we are there for each other, also at the hospital. There were more than 100 people visiting us. That was cool. Yes, and it was all the time he was there, there were people there all the time, and people brought food to my mom and clothes and everything.
>
> Interviewer: And was it your [friends] or friends of the family?
>
> Ahmad's mother: It was friends of the family.
>
> Ahmad's sibling: There were all sorts of people who we do not know at all, who have seen it on Facebook, it was my friends who went there instead of me because I couldn't be there until the day after because of a storm, and it was my mother's friends, it was his friends, it was all kinds of people. I actually cried because I was so grateful that we had so much support in the beginning.

As indicated in the quote, this source of network relations was an important support for the family in the beginning of the rehabilitation process, but, overall, seems to have played a rather peripheral role in relation to the rehabilitation process, by 'only' supporting the family with their presence and material goods during a limited period of time; they did not act as promoters for allocating rehabilitation services.

9.4.4 Family Structure and Social Class

In the family cases constructed in this study, the *split* family structure is represented by the working-class families (those of Agnes, Christian, and William); the *small and weak* family structure is represented by the underclass families (Rasmus and Ahmad); and, finally, the *strong, closed* family is primarily represented by middle-class families (Smilla, and also 'Maria', whose family's case is not detailed above), but also by the working class ('Caroline', whose case, like Maria's, is not discussed in detail in the current text). The same representation was found when exploring the cases of the additional six young people and their families (see Table 9.1). The latter cases also contained families from the upper-middle class (those of 'Harriet' and 'Christine'), which also presented the strong, closed family structure.

Table 9.1 Family structures connected to social class

Class[a]	Small and weak family structure	Split family structure	Strong, closed family structure
Upper class			
Upper-middle class			(Harriet), (Christine)
Middle class			Maria, Smilla
Working class		Agnes, Christian, William	Caroline, (Harry)
Underclass	(Wassim), Ahmad, Rasmus, (Jens), (Marcus)		

Notes: The families of the study's principal eight young persons were interviewed six months after hospitalization. The names of the additional six young persons whose families were interviewed as part of the study are presented in parentheses

[a] Social class designations based on Olsen et al. (2012)

It is notable that, in this analysis, the families with ethnic backgrounds other than Danish belong to the underclass of Danish society and are characterized as having a small and weak family structure. This family structure may be the result of family members not living in the country, and the family members surrounding the injured person already being burdened (e.g., psychologically, physically, financially, socially) before the injury because of the situation that brought them to Denmark. According to statistical studies, there exist ethnic disparities in the risk of traumatic brain injury (Corrigan et al. 2010). The strong representation of the lower social classes in this study is in line with epidemiological studies showing socioeconomic status as a predictor of increased risk of acquiring a traumatic brain injury (Corrigan et al. 2010; Feigin et al. 2010).

9.5 Conclusion

Our approach, following that of Portes, of splitting the phenomenon of social capital into different aspects contributes to a nuanced understanding of how and what kind of a social network can be transformed into the most beneficial assets in a rehabilitation process for young people with an acquired brain injury. Social capital is, in this situation, more potent than economic capital, because money is not the strongest commodity in government-funded rehabilitation. In applying this approach, we have gained an understanding of the inequality that occurs in the rehabilitation process, despite the extended welfare state.

To sum up, we found that the structure and mediated resources of the family, as well as the ability to make use of networks based on ethnicity, are important for the rehabilitation process. Families with a strong, closed family structure were found to be the most successful at transforming their resources in the rehabilitation process—for example, due to the ability to draw on a professional network. This family structure was characterized by resources being concentrated in close, cooperating family members and that subsequently transformed into cultural capital in the rehabilitation process. The identified benefits included both tangible advantages and, to a larger extent, smoothness and continuity in the rehabilitation process. Thus, this type of structure demonstrates the so-called 'Matthew effect' of accumulated advantage (Gladwell 2008), in that credit will be given to those already relatively rich on capital. The small and weak family structure, together with the split family structure, on the other hand, were the least beneficial in the rehabilitation processes of the young persons. These network structures were associated with a low degree of negotiation and cooperation between the family and service professionals, and entailed discontinued and interrupted rehabilitation processes, leaving the families with little influence on the rehabilitation process and their own life situation—a situation that left them relying only on hope.

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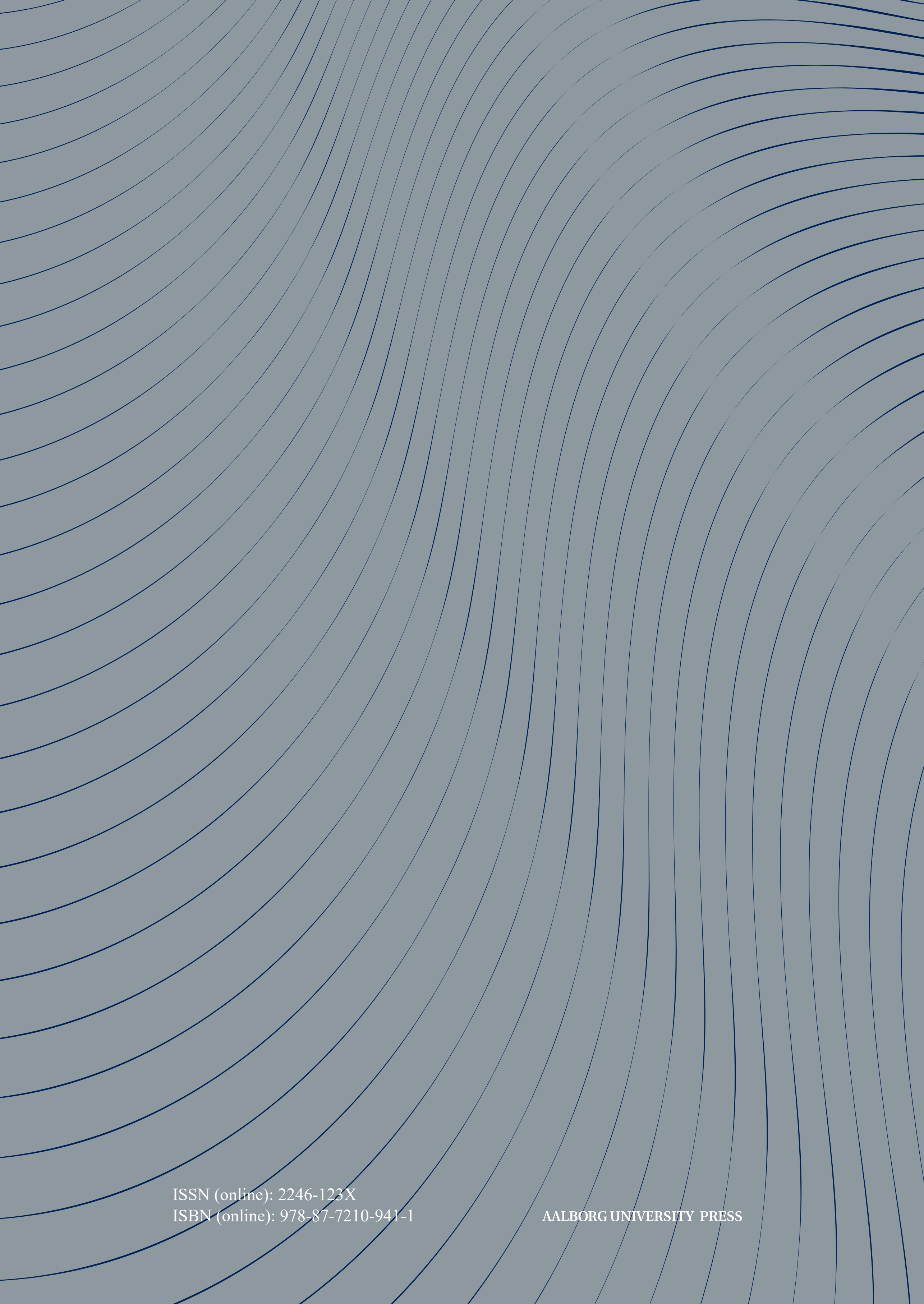

ISSN (online): 2246-123X
ISBN (online): 978-87-7210-941-1

AALBORG UNIVERSITY PRESS