Fatigue following acquired brain injury (FABI)

Advancing methods for treatment and assessment of fatigue for people living with an acquired brain injury

Dornonville de la Cour, Frederik Lehmann

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PhD thesis

31 August 2022

Frederik Lehman Dornonville de la Cour

Faculty of Health Sciences

University of Southern Denmark

Author	Frederik Lehman Dornonville de la Cour Department of Psychology, University of Southern Denmark Cervello
Main supervisor	Ass. Prof. Anne Norup Department of Psychology, University of Southern Denmark Neurorehabilitation Research and Knowledge Centre, Rigshospitalet
Co-supervisors	Dr. Trine Schow Neurorehabilitation Research and Knowledge Centre, Rigshospitalet
	Ass. Prof. Tonny Elmose Andersen Department of Psychology, University of Southern Denmark
Assessment Committee	Prof. Anners Lerdal Department of Interdisciplinary Health Sciences, University of Oslo Research Department, Lovisenberg Diaconal Hospital
	Ass. Prof. Lisa Maria Wu Aarhus Institute of Advanced Studies, Aarhus University Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine
	Ass. Prof. Anders Degn Pedersen Department of Psychology, University of Southern Denmark
Graduate Program	The Graduate School of Health Sciences University of Southern Denmark
Submitted	31 August 2022

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Preface

This research was conducted from 2018–2022 at a specialized brain injury rehabilitation center located in the Zealand Region of Denmark. Ownership of the center was transferred from BOMI to Cervello in 2021. The thesis comprises two parallel research projects concerned with treatment and assessment of fatigue, respectively. They were conducted simultaneously, and papers were prepared and submitted for publication as the respective work was finalized. Throughout each chapter of this thesis, the project concerning treatment is presented first followed by the project on assessment. The numbering of papers corresponds to the order in which they are presented. Further, several labels are used throughout the thesis to describe the people mentioned, including individuals, adults, patients, clinicians, practitioners, service users, service providers, participants, respondents, and informants. Different labels are used intentionally depending on the context of the phrase. For example, study participants are identified as informants in the context of interviews but described as respondents when discussing responses to a questionnaire.

As I have been conducting this research, I have met a large number of people showing great interest in my work. People living with brain injury, struggling with fatigue 24 hours a day; and clinicians, eager to learn more about fatigue due to the challenges that it poses to rehabilitation. Indeed, time after time, I have been reminded of the importance and relevance of this work to people living with brain injury. As such, I am very grateful for the opportunity to conduct this research, and I hope this work will contribute to the advancement of clinical care and guide future research in managing fatigue.

I have enjoyed the help from numerous people along the way. First, I would like to thank my supervisors and co-authors of the papers. Thank you, Dr. Anne Norup, Dr. Trine Schow, and Dr. Tonny Elmose Andersen, for your expertise and guidance throughout the project. Whenever I got lost in details and methodological curiosities, you helped me adopt an eagle-eye perspective and keep my mind on long-term goals.

I would also like to thank Henning Olsen and Kirsten Jensen Quas at BOMI for offering me the opportunity to initiate the project, and I would like to thank Helene Hoffman at Cervello for facilitating the wrap-up of the project. I would further like to acknowledge the contributions of Dr. John Whyte, who provided scientific supervision, and Dr. Karl Bang Christensen and Dr. Morten Andersen, who assisted me on matters of statistical problem solving. A warm-hearted thanks go to Dr. Marianne Løvstad, Daniel Løke, and colleagues at Sunnaas Rehabilitation Hospital for insightful discussions at my stay abroad. Further, I am grateful for the collaboration with Rigshospitalet – Glostrup, Center for Hjerneskade, and Kommunikationscentret, and I would like to express my gratitude to all who participated in the research, helped me collect data, showed interest, and joined in on discussions along the way. Thanks to all colleagues at BOMI, Cervello, University of Southern Denmark, and Neurorehabilitation Research and Knowledge Centre. Especially, I would like to thank my partner, family, and friends for love and support.

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Frederik Lehman Dornonville de la Cour

Roskilde, August 2022

List of Papers

The thesis is based on manuscripts/publications and comprises the following three papers, which are referred to in the text by their numbers I–III (see Appendices A–C).

Paper I

Dornonville de la Cour, F. L., Norup, A., Andersen, T. E., Schow, T. (2022) *Defining a treatment model for self-management of fatigue following acquired brain injury: A collective case study using the Rehabilitation Treatment Specification System* [Manuscript submitted for publication]. Department of Psychology, University of Southern Denmark.

Paper II

Dornonville de la Cour, F. L., Norup, A., Schow, T. & Andersen, T. E. (2021) Evaluation of response processes to the Danish version of the Dutch Multifactor Fatigue Scale in stroke using the Three-Step Test-Interview. *Front Hum Neurosci*, 15, Article 642680. https://doi.org/10.3389/fnhum.2021.642680

Paper III

Dornonville de la Cour, F. L., Schow, T., Andersen, T. E., Petersen, A. H., Zornhagen, G., Visser-Keizer, A. C., Norup, A. (2022) *Measurement properties of the Dutch Multifactor Fatigue Scale in early and late rehabilitation of acquired brain injury in Denmark* [Manuscript submitted for publication]. Department of Psychology, University of Southern Denmark.

Additional Scientific Contributions

The following topic-related scientific contributions were conducted during the PhD project. The work is not included in the thesis.

Dornonville de la Cour, F. L., Bærentzen, M. B., Forchhammer, B., Tibæk, S., & Norup, A. (2022) Reducing fatigue following acquired brain injury: A feasibility study of high intensity interval training for young adults. *Dev Neurorehabil*, 25(5), 349–360

Dornonville de la Cour, F. L., & Norup, A. (2020) Træthed ved erhvervet hjerneskade [Fatigue following acquired brain injury]. In: R. Starrfelt, C. Gerlach, & A. Gade [Eds.], *Klinisk neuropsykologi* (2nd ed., pp. 440–449). Frydenlund Academic.

Abbreviations

ABI	Acquired Brain Injury
AERA	American Educational Research Association
CASM	Cognitive Aspects of Survey Methodology
CFA	Confirmatory factor analysis
CI	Confidence interval
DMFS	Dutch Multifactor Fatigue Scale
DMFS–D	Dutch Multifactor Fatigue Scale–Danish
EFA	Exploratory factor analysis
EM	Energy Management
F.D.	Frederik L. Dornonville de la Cour
MoA	Mechanisms of action
RTSS	Rehabilitation Treatment Specification System
Standards	Standards for Educational and Psychological Testing
T.A.	Tonny E. Andersen
TBI	Traumatic brain injury
T.S.	Trine Schow
TSTI	Three-Step Test Interview
WLSMV	Weighted least squares means and variance adjusted

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Abstract

Fatigue is a common complaint among adults living with an acquired brain injury (ABI). Perceived fatigue can be persistent, disabling, and limiting for reintegration into everyday life. Despite the large impact of fatigue, scientific evidence is limited in guiding clinical practice for treating and assessing fatigue. This thesis comprises two research projects concerning rehabilitation of fatigue following ABI. The first project concerns the development of a treatment model for promoting self-management of fatigue. The second concerns the validation of the Danish translation of Dutch Multifactor Fatigue Scale (DMFS).

In Denmark, a common approach to treating fatigue in neurorehabilitation includes educational and behavioral strategies, termed energy management (EM; *energiforvaltning*). However, the approach is not well defined. Consensus is lacking regarding its components, and underpinning treatment theories are largely unarticulated. **Paper I**, "Defining a Treatment Model for Self-Management of Fatigue Following Acquired Brain Injury: A Collective Case Study Using the Rehabilitation Treatment Specification System", presents a model of EM based on practice-based routines and understandings at a specialized brain injury rehabilitation center. First, an initial model was co-produced with clinicians in iterative workshops using the *Rehabilitation Treatment Specification System*. Next, the model was refined in a collective case study of four individuals in vocational rehabilitation. The EM model comprises five main treatment components: (a) Knowledge and Understanding of Fatigue, (b) Interoceptive Attention of Fatigue, (c) Acceptance of Fatigue, (d) Activity Management, and (e) Self-Management of Fatigue. The model may facilitate theory-driven evaluation research and guide clinical decision-making in tailored treatment.

Treatment planning implies valid assessment instruments. DMFS addresses the multifaceted nature of fatigue following ABI in order to facilitate targeting of treatment to individual needs. DMFS comprises 38 items distributed on five subscales: (a) Impact of

Fatigue, (b) Signs and Direct Consequences of Fatigue, (c) Mental Fatigue, (d) Physical Fatigue, and (e) Coping with Fatigue. A multicenter validation study on DMFS was conducted using both qualitative (Paper II) and quantitative (Paper III) methods. In **Paper II**, "Evaluation of Response Processes to the Danish Version of the Dutch Multifactor Fatigue Scale in Stroke Using the Three-Step Test-Interview", nine adults with stroke were interviewed to investigate interpretative processes involved in responding to DMFS. In **Paper III**, "Measurement Properties of the Dutch Multifactor Fatigue Scale in Early and Late Rehabilitation of Acquired Brain Injury in Denmark", unidimensionality, measurement invariance, and factorial structure of the original subscales were evaluated among 149 adults in rehabilitation of ABI using factor analysis.

Joint results from both papers support validity of the subscales Impact of Fatigue, Signs and Direct Consequences of Fatigue, and Mental Fatigue. Further, they were partially invariant across early versus late rehabilitation settings. Physical Fatigue demonstrated evidence of local dependency, indicated by both interview and factor analyses. Coping with Fatigue was not unidimensional, although response processes were congruent with the intended (multifaceted) construct. Consequently, sumscores are not readily interpreted. The entire scale was multidimensional, but the original factorial structure was not adequately reproduced. Altogether, the three first-named subscales are recommended for measuring fatigue, although constructs may be overlapping. Properties of individual items is analyzed, and item revisions to the Danish translation are recommended.

Several methodological strengths and limitations are considered in the appraisal of findings, including data triangulation, sample size, and generalization. Finally, clinical implications and future perspectives for rehabilitation of fatigue following ABI are discussed, including the prospects of using DMFS as a preassessment tool for targeting EM components to individual needs.

Danish Summary

Træthed er et almindeligt problem for voksne med erhvervet hjerneskade (ABI). Oplevelsen af træthed kan være vedvarende, invaliderende og indskrænkende i hverdagen. På trods af problemet er den videnskabelige evidens begrænset i vejledningen af klinisk praksis for behandling og udredning af træthed. Denne afhandling omfatter to forskningsprojekter om rehabilitering af træthed ved ABI. Det første projekt handler om udviklingen af en behandlingsmodel for at fremme selvstændig håndtering af træthed. Det andet handler om valideringen af den danske oversættelse af Dutch Multifactor Fatigue Scale (DMFS).

En udbredt tilgang til behandling af træthed i dansk neurorehabilitering omfatter pædagogiske og adfærdsmæssige indsatser kendt som energiforvaltning (EM). Tilgangen er dog ikke veldefineret. Der mangler konsensus om dens komponenter, og de understøttende behandlingsteorier er stort set ubeskrevne. **Artikel I**, "Defining a Treatment Model for Self-Management of Fatigue Following Acquired Brain Injury: A Collective Case Study Using the Rehabilitation Treatment Specification System", præsenterer en model af EM ud fra praksis-baserede rutiner og forståelser ved et specialiseret hjerneskaderehabiliteringscenter. Først blev en indledende model udviklet i samarbejde med klinikere i iterative workshops med brug af *Rehabilitation Treatment Specification System*. Herefter blev modellen revideret i et samlet casestudie af fire personer i arbejdsrehabilitering. EM-modellen omfatter fem overordnede behandlingskomponenter: (a) Knowledge and Understanding of Fatigue, (b) Interoceptive Attention of Fatigue, (c) Acceptance of Fatigue, (d) Activity Management, og (e) Self-Management of Fatigue. Modellen kan facilitere teoridrevet evalueringsforskning og vejlede klinisk beslutningstagen i skræddersyet behandling.

Tilrettelæggelsen af indsatser forudsætter valide udredningsværktøjer. DMFS adresserer den multifacetterede karakter af træthed ved ABI for at facilitere målrettet behandling mod individuelle behov. DMFS indeholder 38 items fordelt på fem subskalaer:

(a) Impact of Fatigue, (b) Signs and Direct Consequences of Fatigue, (c) Mental Fatigue, (d) Physical Fatigue og (e) Coping with Fatigue. Et multicenter valideringsstudie af DMFS blev gennemført med brug af kvalitative (Artikel II) og kvantitative (Artikel III) metoder. I **Artikel II**, "Evaluation of Response Processes to the Danish Version of the Dutch Multifactor Fatigue Scale in Stroke Using the Three-Step Test-Interview", blev ni voksne med stroke interviewet for at undersøge fortolkningsprocesser i besvarelsen af DMFS. I **Artikel III**, "Measurement Properties of the Dutch Multifactor Fatigue Scale in Early and Late Rehabilitation of Acquired Brain Injury in Denmark", blev endimensionalitet, målingsinvarians og faktorstruktur af de originale subskalaer evalueret blandt 149 voksne i rehabilitering efter ABI med brug af faktoranalyse.

Fælles resultater fra begge artikler understøtter validiteten af subskalaerne Impact of Fatigue, Signs and Direct Consequences of Fatigue og Mental Fatigue. De var desuden delvist invariante på tværs af tidlige versus sene rehabiliteringsfaser. Physical Fatigue viste evidens for lokal afhængighed, indikeret af både interview- og faktoranalyser. Coping with Fatigue var ikke endimensionel på trods af, at svarprocesser var kongruente med det påtænkte (multifacetterede) konstrukt. Sumscores kan derfor ikke fortolkes uden videre. Hele skalaen var flerdimensionel, men den originale faktorstruktur var ikke tilstrækkelig reproduceret. Alt i alt, de tre førstnævnte subskalaer anbefales til måling af træthed, selvom konstrukterne kan overlappe. Egenskaber ved individuelle items analyseres, og item revisioner anbefales for den danske oversættelse.

Flere metodiske styrker og svagheder overvejes i vurderingen af resultaterne, herunder data triangulering, samplestørrelse, og generalisering. Til sidst diskuteres kliniske implikationer og fremtidige perspektiver for rehabilitering af træthed ved ABI, herunder mulighederne for at bruge DMFS som et udredningsværktøj til at målrette EM komponenter til individuelle behov.

1 Introduction

What does it mean for your everyday life that you are fatigued every day?

> It means that it is difficult for me to make everyday life work. It means that I cannot always do the most basic things. I mean, sometimes I need to choose whether I want to wash clothes, or if I want to cook (…) Just things like cleaning, shopping, cooking, washing clothes – completely basic things like that – to eat, to sit and have something to eat; I am not even always capable of managing that.
>
> —Woman living with stroke sequelae

Talking to people living with an acquired brain injury (ABI) reveals the immense impact of fatigue on everyday life. Fatigue following ABI interferes with multiple aspects of functioning and limits participation in leisure and vocational activities. However, the condition is not easy for people to disentangle and comprehend. Many people struggle with fluctuating symptoms of fatigue long after injury and have difficulties managing fatigue efficiently in daily living.

Fatigue is an inevitable and continuing relevant topic in neurorehabilitation. However, the scientific evidence underpinning means to assessment, treatment, and support for self-management of fatigue is insufficient. Twenty-one years ago, Staub and Bogousslavsky (2001b) published a review entitled “Fatigue After Stroke: A Major but Neglected Issue”, in which they reported that fatigue remains largely unstudied in patients with stroke. Fortunately, the recognition of fatigue has grown rapidly ever since, but despite numerous studies attempting to unravel the mysteries of fatigue, we are left with even more questions than answers (Cumming & Mead, 2015). To this date, fatigue following ABI is arguable a major and recognized yet ever puzzling issue. This thesis focuses on two particular issues related to rehabilitation of fatigue, namely treatment and assessment.

In Denmark, the term energy management (EM; *energiforvaltning*) is used frequently to describe a common approach to rehabilitation of fatigue in routine practice. EM typically refers to a complex and interdisciplinary treatment combining multiple components, including various educational and behavioral strategies, with the aim of empowering individuals to manage symptoms of fatigue in daily living. However, the term is messy without consensus on its definition, contents, and standard practice. Clinicians are – by and large – left to their own device when managing fatigue (Drummond et al., 2022; Riley, 2017), and service provision may vary considerably among service providers (Tremayne et al., 2021). In addition, lack of sufficient treatment descriptions hampers scientific endeavors to document and compare efficacy. Nevertheless, EM remains a well-established practice in neurorehabilitation despite lack of clinical guidelines and scientific evidence.

Another pertinent issue to rehabilitation of fatigue concerns the validity and utility of assessment instruments as a mean to targeting and evaluating treatment. Assessment instruments of fatigue are manyfold without a gold standard or sufficient evidence of validity for neurological populations, including ABI (Tyson & Brown, 2014). Several of the scales in use are generic scales used across various populations, and only few were designed for ABI specifically. The Dutch Multifactor Fatigue Scale (DMFS) was developed as a remedy to the lack of fatigue scales addressing the detailed experience of fatigue following ABI (Visser-Keizer et al., 2015). DMFS comprises multiple subscales, and a particular promising feature is the subscale Coping with Fatigue, which addresses the capability to manage limitations posed by fatigue. Thus, DMFS is promising for targeting treatment to individual needs, but it lacks evidence of validity to support interpretations of test scores and to justify using the scale for tailoring of treatment.

Aims

Fatigue interferes with the everyday life of people living with ABI, and rehabilitation practices are complex, encompassing multiple treatment components. Tailoring these components to individual needs requires detailed assessment of specific problems related to fatigue. As such, the aims of this thesis were:

1. To define a treatment model of EM based on routine practice in rehabilitation of ABI
2. To evaluate test validity of DMFS for measuring aspects of fatigue following ABI

Scope and Outline of the Thesis

This thesis concerns *perceived* fatigue (also termed "subjective" fatigue) as reported by the individual via introspection (the process of observing and interpreting one's own mental states) in contrast to any performance-based operationalizations of the concept, i.e., "objective" fatigue. Thus, the term *fatigue* refers to perceived fatigue (self-reported) throughout the thesis unless specified otherwise. Furthermore, the thesis is concerned with adult populations (≥ 18 years old); research in pediatric populations is not considered.

Following this introduction, the Background chapter clarifies the use of central terms and concepts and provides a focused literature review of previous research on the topic. Next, the Methods chapter presents specific research objectives and provides a summary of research designs and study procedures. The Main Results chapter summarizes results of the original research conducted. In the Discussion chapter, findings and joint implications of the research are discussed in consideration of the methods employed, previous research, and clinical perspectives. Next, methodological considerations are presented followed by future perspectives in rehabilitation of fatigue. Finally, a conclusion on the thesis is provided.

2 Background

Fatigue is an elusive concept difficult to study rigorously. This chapter provides a brief and focused overview of fatigue following ABI and clarifies concepts that will be used throughout the thesis. First, the impact and rehabilitation of ABI is described followed by further details on the burden of fatigue. Next, conceptual issues regarding fatigue will be elaborated. In the last two sections, concerns related to treatment and assessment of fatigue, respectively, will be presented. It is out of scope to provide a systematic literature review.

2.1 Rehabilitation of Acquired Brain Injury

ABI is an acute injury to the brain that is not of congenital or perinatal origin. ABI includes traumatic (e.g., blow or penetrating injury to the head) and non-traumatic injuries (e.g., cerebrovascular diseases, infections, toxins), of which stroke is the most prevalent. In 2019, stroke was the third-leading cause of death and disability worldwide, and the burden of stroke is growing with an ageing population despite improved acute care and increased survival rates (Feigin et al., 2021). Meanwhile, the incidence of traumatic brain injury (TBI) is growing in numbers (James et al., 2019). Thus, the need for rehabilitation services due to stroke and TBI is increasing (Cieza et al., 2020). In Denmark, the Danish Health Data Authority estimated 12.770 hospitalizations from stroke and 7.053 hospitalizations from other causes of ABI in 2017 (Sundhedsdatastyrelsen, 2020). The same year, 8.480 were estimated to need rehabilitation. Prevalence was estimated at 110.973 for stroke and 59.766 for other causes, both rising by 14% and 11%, respectively, since 2011 (Sundhedsdatastyrelsen, 2020).

ABI is responsible for substantial and long-lasting economic costs (A. Chen et al., 2012; Norup et al., 2020). Due to prolonged recovery processes and long-term consequences (Wilson et al., 2017), many patients require ongoing care and rehabilitation beyond hospital discharge. In Denmark, the average costs of treatment and rehabilitation of ABI have been estimated at US$ 36.200 in the first two years post-injury (Sundhedsstyrelsen, 2011). Non-medical costs (e.g., nursing homes, social services) and indirect costs associated with disability such as reduced productivity, work absenteeism, and disability pension add substantially to the total cost (Olesen et al., 2012).

ABI interferes with multiple aspects of functioning and causes a wide range of disabilities, including impairments of body functions (e.g., paresis, cognitive deficits, and emotional problems), activity limitations (e.g., self-care, housework, etc.), and participation restrictions (e.g., mobility, communication, and occupational roles). The severity, range, and complexity of disabilities vary considerably across individuals. Some patients recover quickly with limited impact on functioning, while others require intensive, long-term, and complex interdisciplinary and specialized rehabilitation. The aim of rehabilitation is to reduce the impact of health conditions in order to promote independent living and enable participation in civic life. The World Health Organization (2021) defines rehabilitation as: “A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” (What is rehabilitation? section). To meet the heterogeneous rehabilitation needs, rehabilitation practice and service delivery need to be person-centered (Jesus et al., 2022). The diverse and extensive impact of ABI on multiple aspects of functioning emphasizes the need for treatment tailored to the unique characteristics and circumstances of the individual. Among the consequences of ABI, fatigue is a common complaint and unmet need in rehabilitation.

The Burden of Fatigue Following Acquired Brain Injury

Persistent fatigue is a disabling condition following ABI and interferes with activities and participation in everyday living. Among the problems experienced in life after stroke, fatigue is one of the most incriminating (Ingles et al., 1999) and ranks as a high priority for future research (Pollock et al., 2014; Rudberg et al., 2021). The symptoms of fatigue can be experienced as overwhelming and unpredictable, causing feelings of insecurity, an abnormal need for rest, and diminished capacity to participate in daily activities, including leisure and work (Eilertsen et al., 2013; Ezekiel et al., 2021). People need to adapt everyday living to manage and cope with fatigue (Ablewhite, Nouri, et al., 2022; Teng et al., 2022). Fatigue is associated with no return-to-work (Andersen et al., 2012; Palm et al., 2017), disability (Juengst et al., 2013; Sibbritt et al., 2022), and decreased quality of life (Almhdawi et al., 2021; Cantor et al., 2008; Naess et al., 2006; Tang et al., 2010; van de Port et al., 2007). Altogether, previous research emphasizes the overall burden and unmet needs caused by fatigue.

People with ABI report higher levels of fatigue compared to the general population (Christensen et al., 2008; Naess et al., 2005). However, the prevalence of fatigue is difficult to estimate due to a range of methodological challenges, including issues related to measurement, classification, and sample characteristics. In stroke, a meta-analysis of 22 studies (N = 3,491), all employing the same measurement scale, estimated a pooled prevalence of 50%, 95% confidence interval (CI) [43%, 57%] (Cumming et al., 2016). However, heterogeneity was large, and estimates of individual studies ranged from 25%–85%. Studies in TBI also exhibit substantial variability in prevalence estimates, ranging from 5%–80% among thirteen studies (Mollayeva et al., 2014). To some individuals, fatigue persists for years after injury (Duncan et al., 2012; Mollayeva et al., 2014; Naess et al., 2005). In a longitudinal study (N = 141), fatigue was the most common persistent complaint with

57% reporting fatigue ten years after TBI (Ponsford et al., 2014). Trajectories of post-stroke fatigue vary on an individual level (Duncan et al., 2014) but are relatively stable over time on a group level (Kjeverud et al., 2020). Thus, evidence suggests that complaints of fatigue shortly after injury predicts fatigue in the long term.

2.2 The Concept of Fatigue

In lay terms, fatigue describes a feeling of tiredness, weariness, or lack of energy. It is an ambiguous word used with various meanings in colloquial language, e.g., drowsiness, physical exhaustion, or lack of initiative. The concept is not easily defined due to its subjective and equivocal nature, and there is no unified definition of fatigue as a neurological symptom (Kluger et al., 2013). Despite overlaps, fatigue is distinct from related phenomena such as daytime sleepiness, apathy, and depression (Staub & Bogousslavsky, 2001b). A general definition conceptualizes fatigue as: “A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998, p. 2). Although the definition was developed in context of multiple sclerosis, no element confines it to this condition. The definition may apply to other neurological conditions due to its parsimony.

Other conceptualizations of fatigue in neurological conditions define fatigue in terms of decreased capacity for sustained exertion and perceived effort in voluntary activities (e.g., Chaudhuri & Behan, 2004; Kluger et al., 2013; Staub & Bogousslavsky, 2001b). For example, Aaronson et al. (1999) define fatigue as “the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity” (p. 46). Thus, fatigue manifests as a decreased capacity for activities. However, it can be argued that diminished capacity is a consequence of fatigue rather than a defining feature, although the interference with activities is essential in recognizing “clinically significant” fatigue versus “normal” fatigue (Krupp, 2003).

The Relationship Between Fatigue and Activities

The relationship between fatigue and activities is integral to understanding the concept of fatigue. Evidence suggest that the relationship may be reciprocal, i.e., fatigue affects the ability to perform daily activities, but activities may also affect the experience of fatigue (Eilertsen et al., 2013). Patient perspectives reveal that symptoms of fatigue are not stable but fluctuate throughout the day and week. Certain activities and features of the environment affect these fluctuations by exacerbating symptoms of fatigue, increasing the need for rest, and prolonging recovery periods (Ezekiel et al., 2021). In other words, individuals tire more easily in response to sustained exertion, a concept known as *fatiguability* (Kratz et al., 2019). Thus, the experience of fatigue interacts with the environment (noise, light, etc.) and everyday activities. However, the experience of fatigue is not homogeneous across individuals. Some of those living with stroke describe that fatigue is constantly present, irrespective of previous exertion levels (Ezekiel et al., 2021; Whitehead et al., 2016). Further, some authors define pathological fatigue as a chronic state unrelated to exertion and rest (de Groot et al., 2003).

Domains of Fatigue

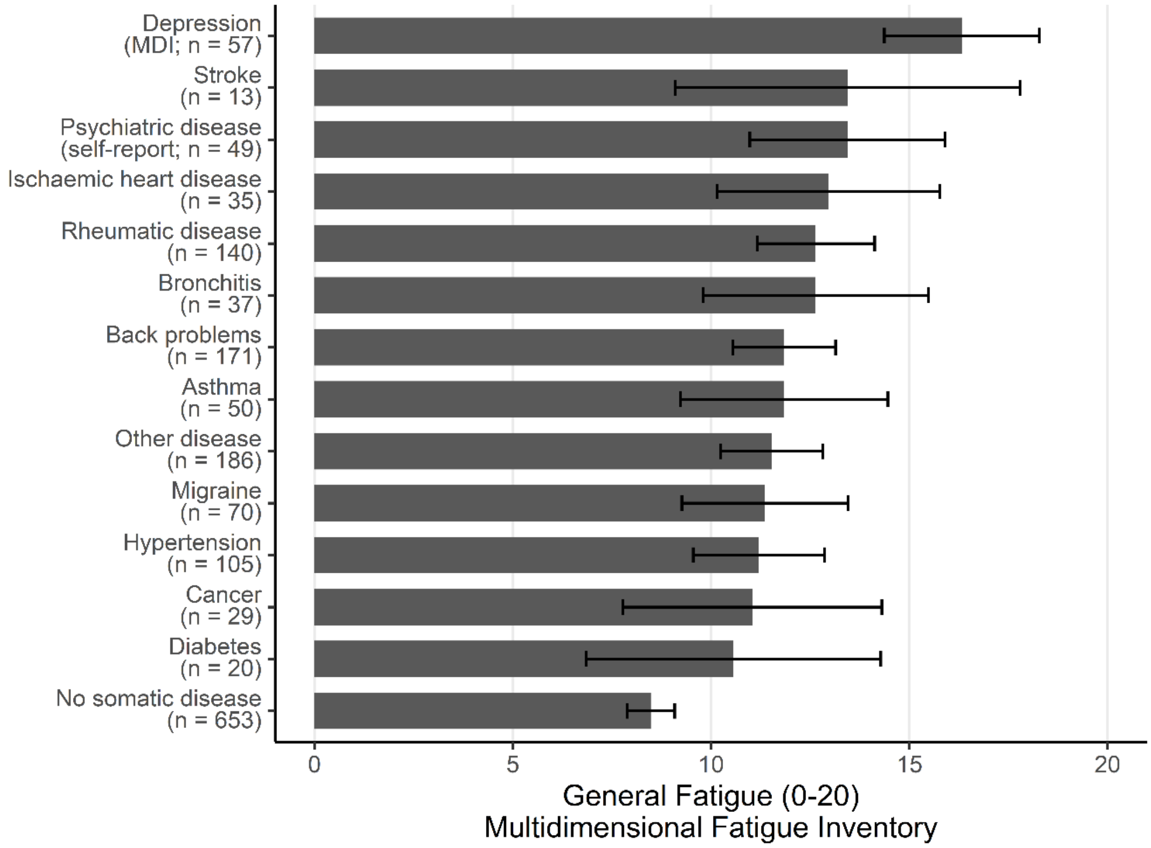
Fatigue is a multifaceted symptom appearing to interact with neurological sequelae. For example, speech-language pathologists report that speech impairments due to aphasia exacerbate (temporarily) in response to fatigue during therapy sessions (Riley, 2017). Likewise, fatigue may respond to mental and physical strain (e.g., sustained concentration or walking with balance problems) and affect mental and physical functioning (e.g., increased irritability or muscle weakness in paretic limbs). Accordingly, some authors propose subtypes of fatigue such as mental fatigue, physical fatigue, psychological fatigue, and somatic fatigue (Staub & Bogousslavsky, 2001a). The notion of mental versus physical fatigue is commonplace in clinical practice (Drummond et al., 2022; Thomas et al., 2019), and the distinction is reflected in several multidimensional fatigue scales (Whitehead, 2009). However, it is unclear whether these domains relate to a unitary construct of fatigue (as manifestations of fatigue) or constitute distinct subtypes of fatigue (Kuppuswamy, 2017). Further, the terms used with fatigue often lack clear definitions (Kluger et al., 2013).

2.3 Treatment of Fatigue

Treatment of fatigue is complicated by the fact that fatigue is not specific to any underlying health condition or physiological state (Chaudhuri & Behan, 2004). Fatigue is a common complaint in many medical conditions such as cancer and autoimmune, rheumatologic, endocrine, infectious, neurological, cardiac, and psychiatric diseases (Krupp, 2003). A study of the Danish general population revealed that perceived fatigue was elevated across all diseases reported compared to the healthy population (Figure 1; Watt et al., 2000). Using the standard cut-off on the Multidimensional Fatigue Inventory (General Fatigue ≥ 12), 32% of the general population were classified as fatigued, 95% CI [29%, 35%] (Christensen et al., 2008). Temporary experiences of fatigue are common even to healthy individuals at various times in life and need not be related to a medical condition (Krupp, 2003). Consequently, any contributing, confounding, and overlapping symptoms, diseases, or states need to be identified and treated accordingly in interdisciplinary rehabilitation (Aarnes et al., 2020; de Groot et al., 2003; Malley et al., 2014). Particularly, the interplay of both pre-, peri-, and post-injury factors need to be considered in planning of treatment (Lerdal et al., 2009; Wu, Mead, et al., 2015).

Figure 1

Mean Levels of Fatigue Across Disease Groups and Healthy Individuals in Denmark



Note. Data from Watt et al. (2000). Error bars show 95% confidence intervals. MDI = Major Depression Inventory.

To date, no reliable biomarker or medical sign of fatigue can be utilized to indicate clinically significant fatigue objectively (DeLuca, 2005a; Kutlubaev et al., 2012). Pathophysiological mechanisms of fatigue following ABI are poorly understood (de Doncker et al., 2018; Schönberger et al., 2017), and perpetuating factors are complex and multifactorial, encompassing biological, psychological, and social factors (Lerdal et al., 2009; Ponsford et al., 2015; Wu, Mead, et al., 2015). Further, multiple secondary factors may influence the perception of fatigue such as deconditioning, sleep, medication, and psychological factors such as depression (DeLuca, 2005b). Accordingly, several treatments targeting various potential mechanisms have been tested in ABI populations (Table 1), often informed by research in other health conditions with prolonged fatigue (Lange et al., 2005). However, evidence is insufficient to recommend any treatment of fatigue in clinical practice (Ali et al., 2022; Cantor et al., 2014; Wu, Kutlubaev, et al., 2015; Xu et al., 2017).

Table 1

Select Treatments of Fatigue Tested in Acquired Brain Injury (ABI) Populations

Treatment modality	Population (reference)
	Pharmacological interventions
Modafinil	Stroke (Bivard et al., 2017; Brioschi et al., 2009; Poulsen et al., 2015), TBI (Jha et al., 2008; P. R. Kaiser et al., 2010), neurological disorders (Sheng et al., 2013)
Methylphenidate	TBI (Johansson et al., 2014, 2015, 2017)
Amantadine	ABI (Ma & Zafonte, 2020)
(−)-OSU6162	ABI (Johansson, Carlsson, et al., 2012)
Antidepressants	Stroke (Choi-Kwon et al., 2007; Karaiskos et al., 2012)
	Non-pharmacological interventions
Cognitive behavioral therapy	Stroke (Nguyen et al., 2019; Wu et al., 2017; Zedlitz et al., 2012), TBI (Nguyen et al., 2017; Raina et al., 2022), ABI (Ymer et al., 2021)
Mindfulness-based stress reduction	ABI (Johansson, Bjuhr, et al., 2012), neurological disorders (Ulrichsen et al., 2016)
Educational/management interventions	Stroke (Boehm et al., 2015; Clarke et al., 2012), ABI (Cooper et al., 2009), chronic conditions (van Heest et al., 2017)
Light therapy	TBI (Sinclair et al., 2014; Srisurapanont et al., 2021), ABI (Connolly et al., 2021)
Physical activity/exercise	TBI (Kolakowsky-Hayner et al., 2017), ABI (Dornonville de la Cour, Bærentzen, et al., 2022)
Transcranial direct current stimulation	Stroke (de Doncker et al., 2021; Dong et al., 2021; Ulrichsen et al., 2021)
Virtual Reality	TBI (Nunnerley et al., 2022)
Multifaceted interventions	Stroke (Hofer et al., 2014), ABI (Stubberud et al., 2019)

Note. References (original research and reviews) were retrieved non-systematically to exemplify respective treatment modalities. TBI = traumatic brain injury.

Energy Management

Frequently, treatments are tested with the aim of reducing severity of fatigue. To a large group of individuals, however, fatigue does not respond to treatment. They continue struggling with fatigue in the long term, and treatments are needed to reduce the impact of fatigue on everyday life. As symptoms of fatigue fluctuate and interact with daily activities and environments, individuals with ABI require knowledge, support, and skills for managing fatigue independently in daily living (Teng et al., 2022). Promoting self-management may counteract vicious cycles in the interplay of fatigue and activities and thereby reduce the frequency and extent of symptom fluctuations, induce feelings of predictability and control, and enable individuals to maintain valued roles despite fatigue. This line of thought is consistent with the central idea of rehabilitation (reducing the impact of health conditions and promote independent living). Accordingly, EM is widely practiced for ABI in neurorehabilitation (Ablewhite, Condon, et al., 2022; Drummond et al., 2022).

However, the practice of EM in rehabilitation of ABI is poorly described. As such, EM may be regarded as a “black box”, i.e., the specific activities and therapeutic processes of treatment are unclear and undefined, and elaborate theories to underpin practice are lacking or remain unarticulated. Consequently, the practice of EM relies on the experience of individual clinicians (Drummond et al., 2022; Thomas et al., 2019). In a survey among 312 speech-language pathologists working with aphasia, the use of fatigue management strategies was more frequently based on clinical experience than formal education or training (Riley, 2017). Thus, a coherent model outlining treatment theory of EM is needed to guide clinical decision-making in person-centered rehabilitation and enable theory-driven evaluation research.

2.4 Assessment of Fatigue

A plethora of questionnaires about fatigue (hereafter, fatigue scales) are available without a gold standard (Hjollund et al., 2007; Whitehead, 2009). Table 2 presents an overview of select fatigue scales, which have been used in ABI populations and translated into Danish. Some are disease-specific (designed for ABI), while others are generic (intended to be used across populations). Evidence of validity for fatigue scales is scarce in neurological populations (Elbers et al., 2012; Tyson & Brown, 2014). Further, scales used in stroke populations address various aspects of fatigue with limited overlap in contents of questionnaires (Skogestad et al., 2019). The lack of a standard definition and clear terminology implies numerous operationalizations of the concept, and the challenges of distinguishing fatigue from related phenomena pose a strong threat to test validity. Consequently, various scales are being used, each measuring different aspects of fatigue with poorly defended claims of validity. This issue impedes comparisons of research findings and hampers scientific progress.

The Dutch Multifactor Fatigue Scale

DMFS was designed to assess the multifaceted nature and impact of fatigue, including coping, following ABI specifically (Visser-Keizer et al., 2015). First, Visser-Keizer et al. (2015) developed a concept scale of 57 items. Items were generated based on interviews with 14 individuals in the chronic phase after ABI (> 6 months) and seven partners. Next, item retention and factorial structure were determined in a sample of 134 individuals with ABI. Nineteen items were excluded, and the remaining 38 items were distributed on five subscales: Impact of Fatigue, Signs and Direct Consequences of Fatigue, Mental Fatigue, Physical Fatigue, and Coping with Fatigue (Visser-Keizer et al., 2015).

Table 2

Select Fatigue Scales in Danish Applied to Acquired Brain Injury (ABI) Populations

Scale name (abbreviation)	Scales	Items	Target population
Fatigue Severity Scale (FSS) [a]	1	9	Generic
Multidimensional Fatigue Inventory (MFI-20) [b]	5	20	Generic
Modified Fatigue Impact Scale (MFIS) [c]	3	21	Multiple sclerosis
Mental Fatigue Scale (MFS) [d]	1	14 + 1	Neurological disorders
Dutch Multifactor Fatigue Scale (DMFS) [e]	5	38	ABI
Barrow Neurological Institute Fatigue Scale (BNI-FS) [f]	1	10 + 1	ABI
Fatigue Scale of Motor and Cognitive Functions (FSMC) [g]	2	20	Multiple sclerosis

Note. Only scales with a primary target of measuring fatigue were considered.

[a] Krupp et al. (1989), Lorentzen et al. (2014). [b] Smets et al. (1995), Watt et al. (2000). [c] Multiple Sclerosis Council for Clinical Practice Guidelines (1998). [d] Johansson et al. (2010). [e] Visser-Keizer et al. (2015), Dornonville de la Cour et al. (2021). [f] Borgaro et al. (2004). [g] Penner et al. (2009), Oervik (2017).

DMFS demonstrated adequate measurement properties in the development sample (Visser-Keizer et al., 2015). The five-factor solution explained 54.7% of variance, and internal consistency of subscales (Cronbach’s α) ranged from .69–.91. Evidence supported convergence with another fatigue scale and divergence with scales of self-esteem and symptoms of depression and anxiety. Subscales exhibited medium to large inter-correlations, except Coping with Fatigue, which was weakly correlated with the other subscales, indicating that it measures a distinct construct (Visser-Keizer et al., 2015).

DMFS was translated into Danish, DMFS–Danish (DMFS–D), using a back-translation procedure (Paper II). To the author’s knowledge, no other validation of DMFS has been conducted to date, and DMFS–D has not been evaluated. Thus, validation is needed to justify the use of DMFS–D and support interpretations of test scores. Further, DMFS was developed and initially tested for people in late stages of ABI (> 6 months). However, recognizing fatigue early in the recovery process is important to determine needs for rehabilitation and treatment. Further, consistent use of the same scale across transitions in rehabilitation facilitates monitoring of recovery over time. Thus, validating DMFS–D in both early and late rehabilitation settings is valuable for the clinical utility of DMFS–D.

Test Validity

The current edition of the *Standards for Educational and Psychological Testing* (hereafter, the Standards) defines test validity as “the degree to which evidence and theory support the interpretations of test scores for proposed uses of tests” (American Educational Research Association [AERA] et al., 2014, p. 11). Thus, validity is not an inherent property of a test but relates to how the test is used. Tests can be used for various purposes implying numerous potential interpretations. Each interpretation requires sound justification based on credible evidence of validity. For example, the intention of determining the level of a given attribute for a particular group of people based on test scores requires sufficient evidence of validity to support this specific inference.

The Standards distinguish five sources of validity evidence: (a) evidence based on test content, (b) evidence based on response processes, (c) evidence based on internal structure, (d) evidence based on relations to other variables, and (e) evidence for validity and consequences of testing (AERA et al., 2014). All available pieces of evidence relevant to an intended interpretation of test scores need to be integrated to make an inference of validity for that specific interpretation. In this context, validation is the process of gathering additional evidence regarding the inferences that can be drawn from a test.

Interim Conclusion

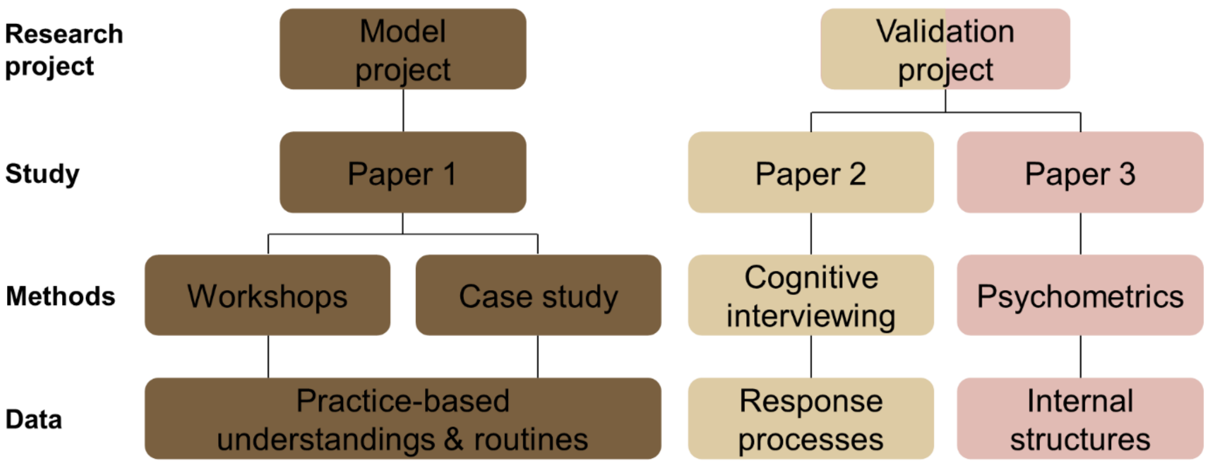
The challenges concerning rehabilitation of fatigue are complex and intertwined. The lack of clear terminology and standard definitions hampers scientific progress in treatment and assessment of fatigue. Without a clear and shared understanding of fatigue, fatigue scales are based on vague and diverse operationalizations, and treatment practices are wide-ranging and ambiguous. Ultimately, valid means of quantifying fatigue and standard descriptions of treatment are needed for evaluation research to provide an evidence base guiding clinical practice.

3 Methods

This thesis comprises three studies (Papers I–III), which are organized in two parallel research projects corresponding to the aims of the thesis (Figure 2). The projects are summarized concurrently throughout the sections of this chapter, as they share common procedures. First, research objectives are stated followed by ethical considerations. Next, research designs and sampling procedures are presented. Thereafter, conceptual frameworks underpinning the three studies are introduced. Finally, methods concerning data collection and data analysis are summarized. The intention is to provide a summary of methods, as detailed descriptions are provided in papers (Appendices A–C). Technical concepts are not elaborated but will be presented with reference to literature providing in-depth explanations.

Figure 2

Overview of Studies in the Thesis



3.1 Research Objectives

The first research project was concerned with defining a treatment model of EM (Aim 1), referred to as the Treatment Model Project. Practice-based knowledge, understandings, and routines were translated into the model. The main research objectives were:

1. To co-produce an initial treatment model with experienced practitioners of EM
2. To refine the initial treatment model based on case analysis of routine practice in EM

The second project was concerned with validating DMFS–D (Aim 2), referred to as the Validation Project. The validation took the original factorial structure proposed by Visser-Keizer et al. (2015) as the starting point. The specific research objectives were:

1. To test if respondents interpret items as expected based on construct theory
2. To test if the original subscales are unidimensional and reliable
3. To test if the original subscales perform equally across early versus late stages of ABI
4. To evaluate the factorial structure of all 38 items of DMFS

Ethical Considerations

Studies were conducted in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2013) and the Danish Code of Conduct for Research Integrity (Ministry of Higher Education and Science, 2014). Permission was not required by the local research ethics committee due to the non-experimental design of the studies (no intervention/trial was introduced) and the nature of data (self-reports). All participants provided written informed consent. Participation was voluntary without reimbursement or economic incentives. Participants and researchers had no relationship prior to enrolment.

3.2 Research Designs and Sampling

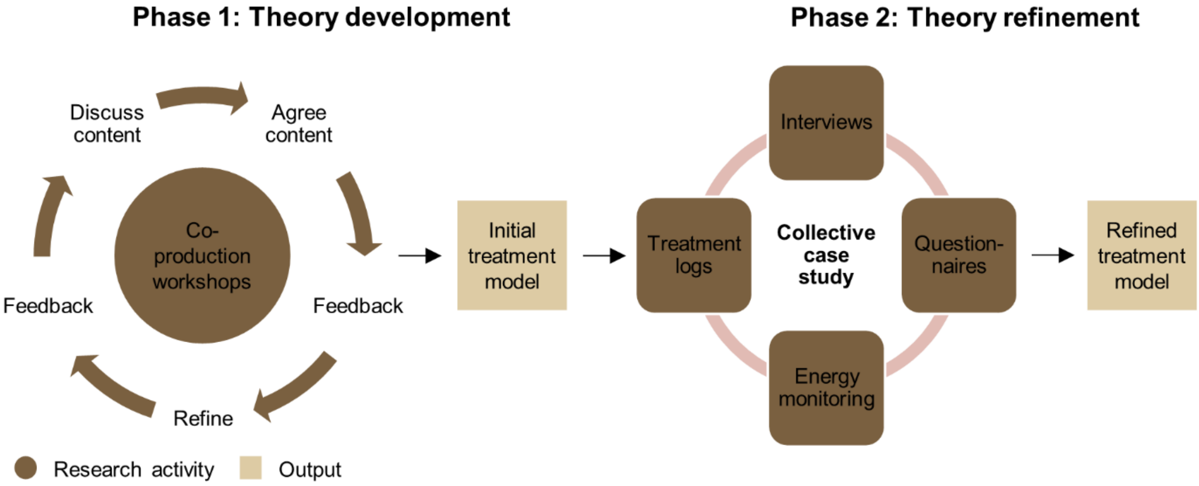
The two research projects employed various research designs. The overall sampling strategy was to represent the heterogeneous ABI population faced in routine practice with the aim of promoting ecological validity of findings. Thus, all participants were recruited in neurorehabilitation settings, and eligibility criteria were relatively inclusive. The first two subsections present research designs and procedures of each project. Next, eligibility criteria are described.

The Treatment Model Project

The study entailed two phases (Figure 3; Paper I). In Phase 1, co-production workshops were conducted in an iterative process to elicit an initial treatment model of EM based on practice-based knowledge and understandings. In Phase 2, a collective case study of routine practice was conducted to refine the treatment model based on case analysis.

Figure 3

Study Design for Development of the Treatment Model on Energy Management



Note. Figure reproduced from Paper I (Appendix A): Dornonville de la Cour, Norup, et al. (2022).

The Study Site. The study was conducted at Cervello, a specialized brain injury rehabilitation center in Denmark. Principal researchers, Frederik L. Dornonville de la Cour (F.D.) and Trine Schow (T.S.), were both employed at the center with easy access to the unit of analysis, i.e., routine practice in EM. Rehabilitation services are provided nationwide within the health sector, the social and welfare sector, and the employment sector. Activities in relation to brain injury rehabilitation include mobile and in-house rehabilitation services, education, training, supervision, and advisory services, and research and development. The rehabilitation center comprises occupational therapists, physiotherapists, neuropsychologists, educational workers, etc. The Danish health care system is tax-based, and citizens in need of rehabilitation receive services free of charge for the individual.

Phase 1: Theory Development. Experienced clinicians at the study site were recruited for an expert group on EM (characteristics are provided in Paper I). A series of co-production workshops were conducted iteratively over 17 months spanning from 2019–2020. F.D. and T.S. facilitated discussions about EM, and F.D. drafted materials for revision at the following meeting. A final draft of the initial treatment model was approved by all group members.

Phase 2: Theory Refinement. A collective case study was conducted prospectively to examine routine practice of EM during a rehabilitation program. All referrals to vocational rehabilitation at the study site were screened for eligibility consecutively over 13 months in 2020–2021, until five participants were enrolled. Eligible subjects were invited to participate by their respective case manager at the start-up meeting of the rehabilitation program. Next, F.D. provided information about the study and screened remaining eligibility criteria requiring self-report. Data were collected throughout the rehabilitation program.

The Validation Project

Two studies were conducted in the validation of DMFS–D, including cognitive interviewing (Paper II) and psychometric evaluation (Paper III).

Cognitive Interviewing. A qualitative study was conducted to investigate interpretative processes in item responding. Clinicians at Cervello invited current and recent service users to participate in the study. F.D. informed about the study and screened for eligibility on the phone. All interviews were conducted over two months in 2019.

Psychometric Evaluation. A cross-sectional multi-center study was conducted to collect responses on DMFS–D. Participants were recruited in four rehabilitation sites in Denmark, including three community brain injury rehabilitation centers and one stroke unit. Clinicians screened for eligibility and recruited participants over 18 months in 2018–2020.

Eligibility Criteria

One set of eligibility criteria were common across all studies: (a) ≥ 18 years old, (b) fluent in Danish, (c) ABI, (d) able to provide informed consent, and (e) no overt cognitive difficulties interfering with participation. ABI was defined according to criteria in *Brain Injury Rehabilitation – A Health Technology Assessment* (Sundhedsstyrelsen, 2011). The following acute disorders causing brain injury were included: Stroke, TBI, and encephalopathy (e.g., infections, toxins, anoxia). Concussion/mild TBI, progressive brain disease (e.g., tumor, neurodegenerative disease, multiple sclerosis), spinal cord injury, and injury of congenital or perinatal origin (≤ 14 days within birth) were excluded.

The case study (Paper I) employed additional eligibility criteria to the ones above: (a) ≤ 65 years old, (b) 3–24 months post-injury, (c) clinically significant fatigue according to the post-stroke case definition (Lynch et al., 2007; Poulsen et al., 2020), (d) no somatic/psychiatric disease causing fatigue, (e) no active alcohol/substance abuse within the latest three months, (f) not retired/withdrawn from the labor market, and (g) no severe mental distress to a degree in which the burden of study participation interferes with outcomes of rehabilitation.

3.3 Conceptual Frameworks

Any scientific investigation implies theoretical assumptions concerning the methods used to study the subject of research. Before proceeding to the analytic procedures, this section summarizes central conceptual frameworks underpinning the methods. First, the *Rehabilitation Treatment Specification System* (RTSS) is introduced, which was used as a framework for the EM model (Paper I). RTSS is a comprehensive framework and only key concepts will be summarized. Next, two frameworks for the validation are described, including the *Cognitive Aspects of Survey Methodology* (CASM) framework (Paper II) and *Latent Variable Theory* of measurement (Paper III).

Rehabilitation Treatment Specification System

RTSS was used to specify treatment theories of EM. A *treatment theory* is a set of claims on "how and why a treatment works to improve some aspect of patient functioning" (Hart et al., 2019, p. 173). RTSS provides (a) a conceptual framework of treatment theory and (b) a theory-driven system for characterizing treatments in rehabilitation (Hart et al., 2019). At its base, RTSS conceptualizes treatment theory in a tripartite structure (Hart et al., 2014):

- Ingredients: The actions of the clinician
- Mechanisms of action (MoA): How actions produce change in outcomes
- Targets: Aspects of functioning directly changed by treatment

(a) Treatment is framed in the strict sense of the word. Treatment theory is only about the actions of clinicians (ingredients) and how those actions directly affect (MoA) aspects of functioning (targets). Any down-stream changes in functioning due to changes in the target are defined as aims. Aims are not a concern of treatment theory but enablement theory, as treatment ingredients only account for these changes indirectly (Whyte, 2014). Thus, achieving a treatment target may enable other aspects of functioning (aims), but that does not explain how and why the treatment works. Ultimately, however, enablement theory is important to the clinical utility of treatment (Whyte, 2014).

Other activities in rehabilitation such as formal assessment and team meetings are not considered treatment (Hart et al., 2019). Due to this narrow scope of the term, what may usually be thought of as one treatment, e.g., cognitive behavioral therapy, may comprise several treatments in context of RTSS. Consequently, each treatment is termed a *treatment component*, and any single session of treatment is likely to include multiple treatment components such as providing information, exercise instructions, opportunities to practice, feedback on performance, etc. Therefore, the number of treatment components needs to be determined as a first step in characterizing treatment (Hart et al., 2019).

(b) *Treatment specification* refers to the process of characterizing treatments according to their treatment theories. For purposes of specification, direct targets are organized in three treatment groups: (a) Organ Functions, (b) Skills and Habits, and (c) Representations, i.e., mental representations such as knowledge and attitudes (Hart et al., 2019). As most rehabilitation treatments require voluntary effort to take effect, additional volition targets sometimes need to be specified (Whyte et al., 2019). The process of specifying treatment involves seven steps (Hart et al., 2018, 2019):

1. specifying the treatment recipient
2. deciding on the direct target of treatment
3. determining the treatment group of the direct target
4. determining whether a volition target is needed
5. articulating the direct target
6. articulating the volition target (if relevant)
7. specifying the ingredients

Cognitive Aspects of Survey Methodology

In its simplest form, the administration of a questionnaire involves the presentation of stimuli and recording of responses. However, the cognitive processes in item responding are integral to identifying sources of response errors, e.g., comprehension of items, retrieval and appraisal of information, and interpretation of response options. CASM (National Research Council, 1984) provides a framework for the study of response processes as a source of evidence in validation research (Padilla & Benítez, 2014).

Cognitive interviewing is a methodological approach based on the CASM framework (Willis, 2005). In broad terms, it is a set of interview methods that tests items of a questionnaire to elicit any response errors. For example, cognitive interviewing may be used to evaluate whether respondents interpret the wording of an item as intended, and findings may indicate specific problems guiding subsequent revisions to items (Willis, 2005). Regarding validation, the analysis of response processes can provide evidence concerning the construct that is inferred to be tapped by the test (AERA et al., 2014). A common approach in cognitive interviewing is to test the fit between expected response processes versus observed response processes (Castillo-Díaz & Padilla, 2013; Launeanu, 2016).

Latent Variable Theory

The psychometric evaluation of DMFS is based on Latent Variable Theory (Borsboom, 2008; Markus & Borsboom, 2013). DMFS intends to measure a psychological attribute, i.e., perceived fatigue. However, the perception of fatigue cannot be observed directly, which poses challenges to measurement. In Latent Variable Theory, an unobservable construct can be measured by treating it as a *latent variable* (Borsboom, 2008). This means that values of fatigue are estimated with a degree of uncertainty based on a set of statistically dependent observed variables. Simply treating DMFS sumscores as observed variables of fatigue implies strong assumptions on measurement (Borsboom, 2008).

In practice, latent variable models estimate expected values of the latent variable based on indicators by specifying falsifiable statistical parameters in a measurement model (Markus & Borsboom, 2013). Validity is a matter of whether the specification of the measurement model is consistent with observed data (Markus & Borsboom, 2013). In context of validation, latent variable models provide evidence concerning the internal structure of a test, i.e., whether the relationship among items conforms to construct theory (AERA et al., 2014). For example, unidimensionality is a common assumption, which implies local independency among items; a proposition that can be tested statistically using latent variable models (Markus & Borsboom, 2013). Latent variable models include both the common factor model and item response theory models. This thesis employed factor analysis, which is based on the common factor model and classical test theory (Brown, 2015; Cappelleri et al., 2014).

3.4 Data Collection and Analysis

First, outcome measures are presented with an emphasis on DMFS. Next, collection and analysis of data is summarized for each study, first the case study (Paper I), then cognitive interviewing (Paper II), and finally the psychometrics study (Paper III). Finally, procedures for determining target sample sizes are described followed by a listing of the analytic software. All interviews were conducted one-on-one, audio recorded, and transcribed verbatim, and standardized outcome measures were administered on paper.

Standardized Outcome Measures

All standardized outcome measures are outlined and characterized in Table 3.

Table 3

Standardized Outcome Measures Used Across Studies (in Danish)

Test	Description
Dutch Multifactor Fatigue Scale (DMFS) [a]	Five scales (38 items in total) Aspects of perceived fatigue following ABI
Post-Stroke Fatigue Case Definition [b]	Structured interview Clinically significant fatigue
Depression Anxiety Stress Scales (DASS–21) [c]	Three scales (21 items in total, 7 each) Symptoms of depression, anxiety, and stress
EQ-5D-5L [d]	Three measures (profile, index, and VAS) Health-related quality of life on five dimensions
Pittsburgh Sleep Quality Index (PSQI) [e]	Seven components and a global score (10 items) Perceived sleep quality
General Self-Efficacy (GSE) scale [f]	One scale (10 items) General perceived self-efficacy
Readiness for Return-to-Work (RRTW) scale [g]	Four scales (13 items in total) Aspects of perceived work readiness

Note. ABI = acquired brain injury; VAS = Visual Analogue Scale.

[a] Visser-Keizer et al. (2015), Dornonville de la Cour et al. (2021). [b] Lynch et al. (2007), Poulsen et al. (2020). [c] Lovibond and Lovibond (1995). [d] Rabin and De Charro (2001), Herdman et al. (2011). [e] Buysse et al. (1989). [f] Schwarzer and Jerusalem (1995). [g] Franche et al. (2007).

Dutch Multifactor Fatigue Scale. DMFS (Visser-Keizer et al., 2015) comprises 38 items distributed on five subscales: Impact of Fatigue (11 items), Signs and Direct Consequences of Fatigue (9 items), Mental Fatigue (7 items), Physical Fatigue (6 items), and Coping with Fatigue (5 items). Items are formulated as statements, e.g., “I am often tired”, and share the same response format. Response options are offered on a 5-point Likert-type scale (scored 1 through 5), anchored with the terms: *no, I strongly disagree*; *I mostly disagree*; *neutral*; *I mostly agree*; and *yes, I strongly agree*. Nine items are reverse keyed. Generally, greater scores indicate worse problems. Constructs are described narratively in Visser-Keizer et al. (2015) and summarized in Paper II. DMFS–D is provided in Appendix D.

The Treatment Model Project

The case study (Paper I) employed multiple data collection methods, including (a) post-rehabilitation interviews, (b) treatment logs, (c) self-monitoring of day-to-day energy levels, and (d) standardized outcome measures. No formal data were collected in co-production workshops during Phase 1 of the study.

Quantitative Data. All standardized outcome measures in Table 3 were collected by F.D. at inclusion and at the end of rehabilitation. An online survey was administered to service users by e-mail at the end of the week to monitor day-to-day energy levels for each weekday. Descriptive statistics and visualizations of quantitative data were conducted.

Qualitative Data. Both service users and service providers were interviewed by F.D. at the end of rehabilitation to elicit information on how participants interacted with the program. An interview guide (Appendix E) was developed based on RAMESES II resources (Wong et al., 2017) using a realist approach (Pawson & Tilley, 1997). Further details on the design of interviews are provided in Paper I. In addition, service providers kept an online RTSS-based treatment log during rehabilitation. An entry was made after each session, including a written a summary of up to three pairs of ingredients, MoA, and targets.

Interview transcripts (n = 8) and log entries (n = 76) were analyzed thematically by F.D. in collaboration with T.S. On a first order level, data were coded according to RTSS terms using a coding protocol consisting of the following categories: (a) Ingredients, (b) Context, (c) Actors, (d) MoA, and (e) Outcomes, divided in Targets and Aims. The protocol is provided in Paper I. Initial coding was verified by T.S. On a second-order level, F.D. themed data units de novo to describe essential features of data in relation to first-order categories. Findings were compiled across cases, and themes were contrasted, defined, and reorganized iteratively in a second-cycle coding process. F.D. maintained a research journal of decisions and interpretations during analysis.

Next, treatment components were specified using RTSS, following the algorithm in *Manual for Rehabilitation Treatment Specification* (Hart et al., 2018). First, themes in the Targets category were used to specify direct targets. Thereafter, relationships were identified among themes in the Targets and Ingredients categories to specify ingredients of treatment components. Finally, the initial treatment model was refined based on the case analysis.

Cognitive Interviewing

Data Collection. Cognitive interviewing (Paper II) was conducted using the Three-Step Test Interview (TSTI) procedure (Hak & Jansen, 2008). First, informants responded to DMFS–D while thinking aloud, i.e., verbalizing every thought coming to mind. Second, the interviewer probed any observed response difficulties. Third, the interviewer probed response processes to each item, including the reasoning process (e.g., "how did you arrive at that answer?") and comprehension (e.g., "what does the word 'physical condition' mean to you?"). Interviews were conducted by F.D. and a trained master's student in Psychology. The interview guide is provided in Appendix F.

Data Analysis. Transcripts from TSTI were analyzed using framework analysis (Ritchie & Spencer, 2002) to determine whether observed response processes were congruent with expected response processes based on construct theory. In practice, each item per respondent was coded using a pre-defined index, based on previous research (Bunzli et al., 2018), to characterize the response process (Table 4). F.D. and Tonny E. Andersen (T.A.) coded data independently and arrived at a final consensus coding through discussion. Category frequencies were summarized per item, and transcripts were reviewed to assess the nature of any response difficulties or incongruencies with construct theory.

Table 4

Index Categories in Analysis of Three-Step Test Interview Transcripts

Category	Description
1. Congruent	"Observed response was related to the subscale construct"
2. Incongruent	"Observed response was not related to the subscale construct"
3. Ambiguous	"Observed response was both congruent and incongruent or insufficient to determine congruency"
4. Confused	"Observed response was generated based on comprehension difficulties"

Note. Descriptions quoted from Paper II (Appendix B): Dornonville de la Cour et al. (2021).

Psychometrics

Data Collection. DMFS–D, the 21-item Depression Anxiety Stress Scales (Lovibond & Lovibond, 1995), and EQ-5D-5L (Herdman et al., 2011; Rabin & de Charro, 2001) were administered to participants in community rehabilitation centers. To limit response burden, participants in the stroke unit responded to DMFS–D only. Clinicians collected data as part of routine practice. Further details are provided in Paper III.

Data Analysis. Unidimensionality was analyzed separately for each of the five original subscales using (a) item descriptive statistics and (b) confirmatory factor analysis (CFA). Next, factorial structure was analyzed using (c) exploratory factor analysis (EFA). EFA was added to the analyses reported in papers. Missing data were handled using listwise deletion for CFA and pairwise deletion for EFA due to low rates of missing data (< 5%).

(a) Item descriptive statistics were analyzed based on recommendations of DeVellis (2017). Response distributions, item means and standard deviations, inter-item correlations (polychoric correlation coefficient), and corrected item-scale correlations (tetrachoric correlation coefficient) were compared across items to detect any deviant items. Further, monotonicity was evaluated across all values of the corrected scale score using locally estimated scatterplot smoothing curves.

(b) Each original subscale was specified in CFA using five separate one-factor models. Indicators were treated as ordinal variables using weighted least squares means and variance adjusted (WLSMV) estimation with delta parameterization. In addition, models were fitted using multiple-groups CFA to test measurement invariance across rehabilitation settings: early (stroke unit) versus late (community rehabilitation centers). The procedures for measurement invariance testing followed guidelines by Svetina et al. (2020) and are elaborated in Paper III. Scale reliability was estimated using McDonald's (1999) ω total coefficient for ordinal items (Green & Yang, 2009). Fit indices and applied criteria for determining overall goodness-of-fit and reliability are provided in Table 5, based on guidelines by Brown (2015) and Chen (2007). Sources of ill fit for misfitting models were analyzed using modification indices and residuals (Brown, 2015).

Table 5

Criteria for Overall Goodness-of-Fit and Reliability in Confirmatory Factor Analysis

Index	Model fit/reliability		Relative model fit
	Adequate	Mediocre	Invariance
RMSEA	≤ 0.08	0.08–0.10	Δ < 0.010
CFI	≥ .90		Δ > -.005
TLI	≥ 0.90		
ω	≥ .70		

Note. Relative model fit was evaluated among nested models in measurement invariance testing. RMSEA = root mean square error of approximation; CFI = comparative fit index; TLI = Tucker-Lewis index; Δ = change; ω = McDonald's omega total coefficient.

(c) In EFA, factors were extracted using principal axis factoring of the polychoric correlation matrix. The Kaiser-Meyer-Olkin coefficient (H. F. Kaiser & Rice, 1974) was .64, indicating adequate sampling for EFA according to criteria reported by H. F. Kaiser (1974). Bartlett's (1951) test of sphericity was statistically significant, $\chi^2(703) = 3998.65$, $p \leq .001$, indicating a suitable correlation matrix. Factor selection was determined using Horn's (1965) parallel analysis. The factor solution was rotated using varimax. In consistency with Visser-Keizer et al. (2015), > .40 was used as cut-off for determining salience of factor loadings.

Target Sample Sizes

Case Study. Due to the emphasis on qualitative research, this study (Paper I) was not concerned with statistical generalization but analytic generalization, i.e., providing a rich, contextualized account of EM practices to inform theory (see Polit & Beck, 2010). Thus, a target of five cases was determined a priori based on traditions in collective case study methodology (Crowe et al., 2011).

Cognitive Interviewing. Target sample size was determined at ten based on available guidelines (Paper II). COSMIN standards recommend at least seven participants to be classified as "very good" for cognitive interviewing (Terwee et al., 2018). Consistently with these guidelines, Willis (2005) recommends 5–15 participants.

Psychometric Evaluation. For statistical analyses (Paper III), target sample size was determined at 150 based on recommendations for factor analysis by Mundfrom et al. (2005). DMFS comprises 38 items distributed on five factors, equal to an average 7.6 variables-to-factor ratio. Assuming a wide range of communalities (.2 < .8), a sample size between 130–150 was estimated to be sufficient to achieve excellent agreement between sample and population values (minimum coefficient of congruence = 0.98; Mundfrom et al., 2005).

Analytic Software and Data Transparency

Qualitative analysis was conducted in *NVivo* 1.6.1 (QSR International Pty Ltd., 2020). All statistics and plots were computed in *R* version 4.2.0 (R Core Team, 2022). CFA was conducted using the *lavaan* (Rosseel, 2012) and *semTools* (Jorgensen et al., 2021) packages, and reliability was computed using *MBESS* (Kelley, 2020). EFA, correlational, and descriptive analyses were conducted using *psych* (Revelle, 2020), and graphs were computed using *ggplot2* (Wickham, 2016). Summary data (correlation matrices) for psychometric analyses are provided in supplemental materials to Paper III (Appendix C).

4 Main Results

Results of the two research projects are summarized separately in two main sections. As the objective is to provide a summary of main results, illustrative quotes, detailed statistics, and extended elaborations can be found in respective papers (Appendices A–C).

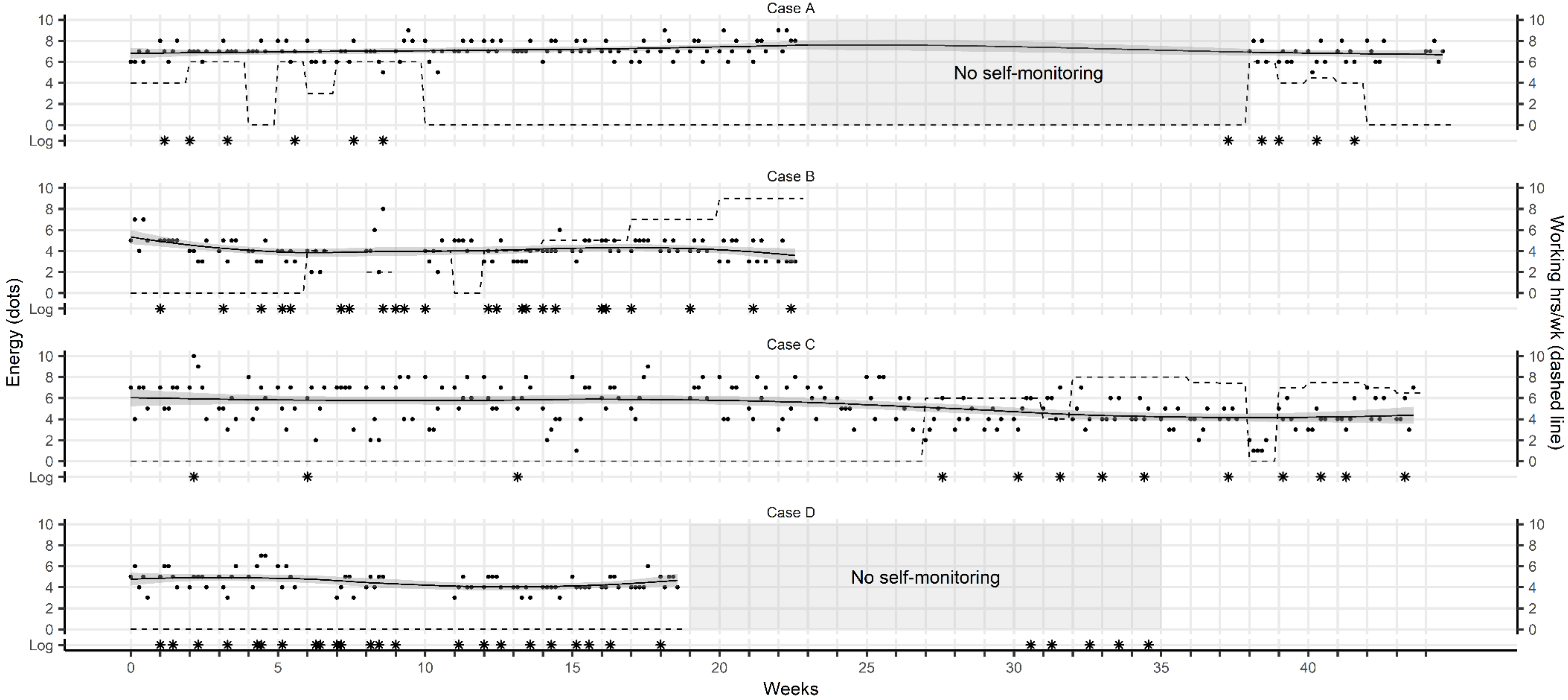
4.1 The Treatment Model Project

An initial treatment model of EM was co-produced with practitioners (Phase 1) and subsequently refined based on case analysis (Phase 2). The scope of the model was narrowed down during the study, whereby some treatment targets were discarded, and other targets were reorganized and redefined (see Paper I for further details). The EM model is strictly concerned with reducing the impact of fatigue, and treatments to reduce the severity of fatigue (e.g., by treating contributors to fatigue) were excluded. The initial model is provided in Appendix G.

Case Descriptions. Four participants completed the study, including two women and two men aged 57–62 years. All had a stroke (7–12 months previously at inclusion) and experienced clinically significant fatigue. Detailed case characteristics and standardized outcome measures are provided in Paper I. Rehabilitation spanned from 23–45 weeks (Figure 4). Some programs were delayed due to covid-19 lockdown. Day-to-day energy trajectories were relatively stable (Figure 4). However, self-rated energy levels tended to decrease as working hours increased. Further, mean energy levels and fluctuations differed across cases.

Figure 4

Energy Levels and Working Hours in the Course of Vocational Rehabilitation for Four Adults Living with Stroke Sequelae



Note. Figure reproduced from Paper I (Appendix A): Dornonville de la Cour, Norup, et al. (2022). Dots show day-to-day energy self-monitoring (0–10). Solid lines show trends in energy using locally estimated scatterplot smoothing with 95% confidence intervals. Dashed lines show self-reported working hrs/week. Asterisks show timing of treatment sessions.

The Refined Treatment Model on Energy Management

The refined EM model outlines treatment components for promoting self-management of fatigue. The model is provided in Table 6, and elaborated descriptions are provided in Paper I. The model includes five main treatment components:

- Knowledge and Understanding of Fatigue
- Interoceptive Attention of Fatigue
- Acceptance of Fatigue
- Activity Management
- Self-Management of Fatigue

Knowledge and Understanding of Fatigue. This is a target of enhancing knowledge and understanding of subjective experiences of fatigue as a consequence of ABI. Multiple domains of knowledge were specified in case analysis such as interactions between fatigue and activities, triggers of fatigue, and limitations due to fatigue (Table 6). Ingredients include providing semantic information, guiding the use of a fatigue/activity diary, and comparing personal experiences of fatigue with general information about fatigue.

Interoceptive Attention of Fatigue. The second target is about improving the ability and forming a habit of noticing and responding to early signs of fatigue (proactively). Signs include bodily sensations (pain, headache, weariness, etc.) and behavioral changes (yawning, distractibility, irritability, aggravated symptoms of paresis, aphasia, etc.). Accordingly, the target implies knowledge of signs of fatigue. Examples of ingredients include guiding the use of a 10-point energy scale (to delineate nuances in experiences of energy/fatigue), teaching mindfulness techniques, and directing attention to overt signs of fatigue (Table 6).

Table 6

The Refined Energy Management Model: Summary of Treatment Components

Target	Group	Ingredients
KNOWLEDGE AND UNDERSTANDING OF FATIGUE		

Enhanced knowledge and understanding of fatigue:
• The concept of fatigue as a consequence of injury
• Interactions between fatigue symptoms and activities
• Triggers of fatigue symptoms
• Signs and symptoms of fatigue
• Limitations posed by fatigue
• Needs due to fatigue in daily life
	R	• Provide semantic information on fatigue (verbally or using visual models/analogies)
		  ◦ Discuss how information applies to experiences; Share peer experiences; Discuss responses on formal assessment
		• Fatigue/activity diary in any preferred format
		  ◦ Provide rationale and instructions for use and tailor the format to individual needs; Provide opportunities for use at home; Troubleshoot any barriers
		• Guided analysis of diary entries
		  ◦ Probe reasons for fluctuations in energy levels; Query effects of various activities, life circumstances, and changes in daily routines; Categorize activities by effect
		• Query early signs of fatigue in recent situations

INTEROCEPTIVE ATTENTION OF FATIGUE		

• Increased ability to notice signs of fatigue
• Form a habit of responding to signs of fatigue
	S	• Guided use of a 10-point energy scale
		  ◦ Query sensations on different levels of the scale; Encourage and guide use at home
		• Fatigue/activity diary (see Knowledge and Understanding of Fatigue)
		• Guided practice in mindfulness techniques
		  ◦ Provide rationale and instructions; Provide opportunities to practice at home
		• Discuss reactions to symptoms of fatigue and management options
		• Direct attention to overt signs of fatigue and guide use of management strategies

ACCEPTANCE OF FATIGUE		

• Increased recognition of fatigue as a chronic condition
• Adapted expectations to current functional level
	R	• Acknowledge the impact of fatigue
		  ◦ Document fatigue by formal assessment; Discuss limitations posed by fatigue
		• Discuss expectations regarding recovery/persistence of fatigue
		• Discuss current vs. previous functional level
		  ◦ Challenge perspectives on life roles, core values, and identity
		• Opportunities for sharing peer experiences

Target	Group	Ingredients
ACTIVITY MANAGEMENT		

Form a habit of managing fatigue in daily activities:
• Scheduling activities
• Planning according to anticipated energy levels
• Alternating periods of activity/rest
• Reappraising activities
• Managing tasks efficiently
	S	• Week planner, daily schedule, etc.
		  • Encourage regular use
		• Guided practice in planning activities based on energy conservation strategies:
		  • Distribute exerting activities; Plan rest and recovery ahead of exertion; Plan regular rests/breaks; Adjust (and grade) overall activity level
		• Provide opportunities to practice planning at home
		  • Provide rationale and instructions; Troubleshoot any barriers for using planning strategies; Evaluate effects with recipient
		• Encourage intermittent breaks and activity pacing
		• Probe valued activities, duties, and responsibilities
		  • Encourage prioritization and guide if needed; Encourage redelegating tasks or suggest alternative solutions to managing duties; Troubleshoot barriers for engaging in valued activities
		• Encourage strategies to reduce physical and cognitive load in daily task management

Increased ability to rest efficiently	S	• Provide opportunities to test relaxation techniques and types of rest at home • Query preferences and provide information; Troubleshoot any barriers; Evaluate effects with recipient
SELF-MANAGEMENT OF FATIGUE		
Increased confidence in one’s ability to manage fatigue in daily living	R	• Graded support/independence in implementation of strategies as needed • Evaluate effects of strategies with recipient • Query options for managing fatigue in challenging situations in daily life

Note. Table reprinted from Paper I (Appendix A): Dornonville de la Cour, Norup, et al. (2022). The treatment model was specified using the Rehabilitation Treatment Specification System. All targets are direct targets involving recipient volition. S = Skills and Habits, R = Representations.

Acceptance of Fatigue. This target concerns increasing recognition and acknowledgement of the condition of fatigue and aligning expectations to oneself with the limitations posed by fatigue. Ingredients include discussing previous vs. current functional level, valued roles and activities, and the expectations for recovery/persistence of fatigue (Table 6).

Activity Management. This target is concerned with learning skills and forming habits for managing fatigue efficiently in everyday activities. Multiple domains were specified such as learning strategies for resting, reappraising activities, and adopting a routine of scheduling daily activities in consideration of anticipated energy levels and risk of exacerbating symptoms of fatigue (pacing activities, distributing exerting activities, planning regular rests and intermittent breaks, etc.). Ingredients include querying preferences for resting, discussing prioritization and how daily tasks are managed, and guiding activity planning (Table 6).

Self-Management of Fatigue. The final component is about increasing self-efficacy in fatigue management, i.e., feeling confident in one's ability to manage fatigue independently in daily living. This target includes improving one's confidence in (a) knowing how to avoid fatigue from worsening and (b) knowing what to do when fatigue gets worse. Ingredients include gradually increasing independence when practicing and implementing strategies in daily life and querying options for managing fatigue in various situations (Table 6).

4.2 The Validation Project

Following a brief description of samples, this section summarizes main results concerning response processes (Paper II) and internal structures (Paper III) as validity evidence for the original subscales of DMFS. First, the overall performance of original subscales is summarized followed by more detailed results on properties of individual items within subscales. Next, the performance of subscales across rehabilitation settings is summarized. Finally, results are presented regarding the factorial structure of DMFS–D.

Sample Characteristics. Nine adults with stroke participated in cognitive interviewing (Paper II). Mean age was 55 years (*SD* = 6.3), median time since injury was 26 months (range = 10–34), and five were female. The sample for the psychometrics study (Paper III) comprised 149 adults with ABI, 92.6% with stroke, 37.6% female, and *M* = 58.4 years old (*SD* = 12.6). Forty-nine were recruited in the stroke unit, *M* = 10.5 days post-stroke (*SD* = 10.5), and 100 were recruited in community rehabilitation centers, *M* = 540.8 days post-injury (*SD* = 801.3), equal to 17.8 months.

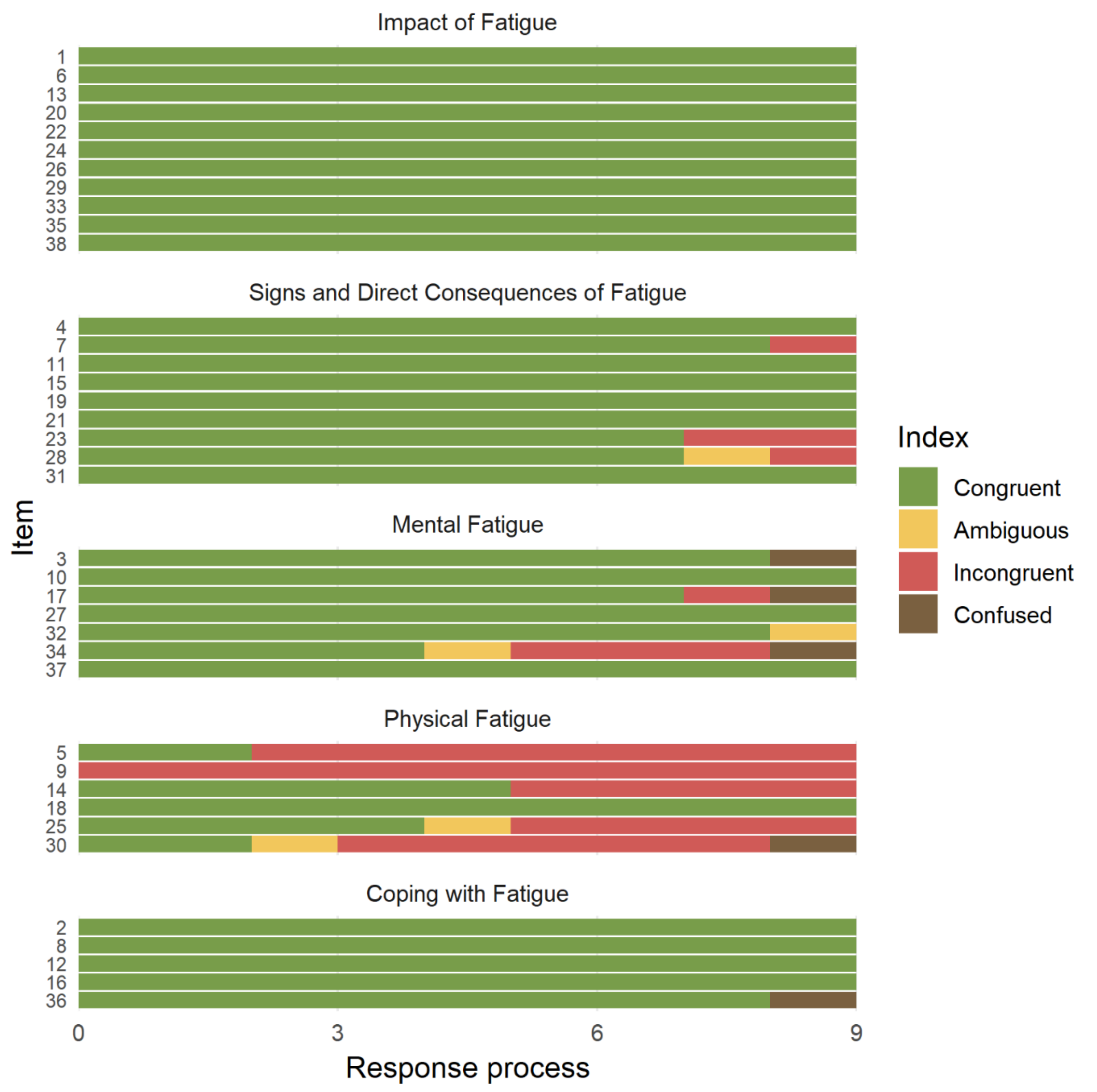
Main Results Across Subscales

Research Objective 1: Response Processes. Figure 5 shows distributions of response processes with respect to congruency. Twenty-five items were 100% congruent with the intended construct. Contrarily, five items exhibited non-congruent responses in > 50% of cases. Of these, four items were belonging to Physical Fatigue and one to Mental Fatigue. In addition, various response difficulties unrelated to construct congruency were observed for seven items (not illustrated in Figure 5; see Paper II, Appendix B, for a full description).

Research Objective 2: Internal Structures. Overall goodness-of-fit and reliability estimates of CFA models are reported in Table 7. No subscale provided excellent fit to data. However, Impact of Fatigue, Signs and Direct Consequences of Fatigue, and Mental Fatigue exhibited adequate overall fit and reliability. Physical Fatigue and Coping with Fatigue exhibited misfit, indicating violations of the assumption of unidimensionality. Descriptive statistics and intercorrelations of subscale scores are reported in Paper III (Appendix C).

Figure 5

Congruency of Response Processes to Dutch Multifactor Fatigue Scale–Danish



Note. Figure reproduced from Paper II (Appendix B): Dornonville de la Cour et al. (2021). *N* = 9. Index categories are defined in Table 4.

Table 7

Goodness-of-Fit and Reliability of Subscales on Dutch Multifactor Fatigue Scale–Danish

Model	χ^2			RMSEA		CFI	TLI	ω	
	Value	*df*	*p*	Value	90 % CI			Value	95 % CI
IF [a]	73.37	44	.004	0.068	[0.039, 0.094]	.981	0.977	.90	[.86, .92]
SC [b]	51.01	27	.003	0.078	[0.044, 0.110]	.944	0.925	.80	[.71, .85]
MF [c]	23.11	14	.058	0.067	[0.000, 0.113]	.985	0.978	.83	[.76, .87]
PF [c]	40.64	9	< .001	**0.155**	[0.108, 0.204]	.918	**0.863**	.76	[.65, .82]
CF [c]	22.06	5	.001	**0.152**	[0.091, 0.220]	**.806**	**0.613**	**.46**	[.15, .61]

Note. Separate one-factor models were fitted using WLSMV with delta parameterization in *R* v. 4.2.0 using *lavaan*. Values indicating inadequate fit/reliability are in bold. RMSEA = root mean square error of approximation; CFI = comparative fit index; TLI = Tucker-Lewis index; ω = McDonald's omega total coefficient; CI = confidence interval; IF = Impact of Fatigue; SC = Signs and Direct Consequences of Fatigue; MF = Mental Fatigue; PF = Physical Fatigue; CF = Coping with Fatigue.

[a] N = 147. [b] N = 149. [c] N = 148.

Item Performance by Subscale

Next, main results are elaborated by subscale. Item response distributions, item descriptive statistics, and monotonicity plots are provided in supplementary materials to Paper III (Appendix C).

Impact of Fatigue. Despite adequate psychometric properties of the subscale (Table 7) and congruent response processes (Figure 5), Item 24 "I don't need to have a rest to make it through the day" performed relatively poorly compared to the other items. Three informants had difficulties responding to Item 24 due to syntactic complexity associated with negative wording (Paper II). Further, correlations of Item 24 were weak, and the factor loading was relatively small, although statistically significant (Paper III). Response processes also revealed translational issues concerning Item 29 “Fatigue is my most serious problem”. The word “problem” was translated into a professional term similar to “complaint”, and this term caused confusion to some informants.

Signs and Direct Consequences of Fatigue. Cognitive interviewing revealed that two items were vague to some participants due to ambiguous terms: Item 7 “Emotional issues make me tired” and Item 15 “Other people notice that I am fatigued, before I do” (see Paper II for an elaboration). Item statistics did not indicate any problems (Paper III).

Mental Fatigue. Item 34 “My complaints get worse when I am fatigue” was non-congruent with the intended construct in 5/9 cases. Informants referred to complaints unrelated to mental fatigue or did not know how to rate the item due to the ambiguity of “complaints” (Paper II). In addition, three participants had difficulties responding to Item 17 “A lot of stimulation, such as activity or noise, makes me fatigued”, because the item was double-barreled. Further, Item 3 “I can follow conversations without getting tired” was vague to some participants, as it depended on the nature of the conversation. All items performed well statistically, although Item 3 performed relatively worse than the other items (Paper III).

Physical Fatigue. The model provided poor fit (Table 7), and subsequent analysis of misfit revealed evidence of local dependency among Items 5 “I feel physically fit” and 9 “I have a good physical condition” (Paper III). Post-hoc respecification of the model to account for local dependency confirmed this issue (see Paper III). Consistently with this finding, both Items 5 and 9 were frequently incongruent, as participants tended to refer to general health concerns, cardiorespiratory fitness, and physical disabilities due to hemiparesis (Paper II). Items 25 “My body aches when fatigued” and 30 “I have little energy” were also frequently incongruent, as informants did not refer to physical fatigue (see Paper II). Finally, Item 14 “After a good night’s sleep, I wake up rested” presupposes a good night’s sleep, and one participant rated the item based on never having a good night’s sleep.

Coping with Fatigue. Consistently with results indicating misfit (Table 7), several item pairs were negatively correlated, and some items exhibited weak correlations with the corrected scale score (Paper III). In contrast to these results, the majority of response processes to items were congruent with the intended construct (Paper II).

Performance Across Rehabilitation Settings

Research Objective 3. Due to inadequate model fit, Coping with Fatigue was not subjected to measurement invariance testing. Further, Physical Fatigue was specified with a freely estimated error correlation among Items 5 and 9 to account for local dependency. Finally, Impact of Fatigue failed to converge in multiple-groups CFA. As Item 24 performed poorly, a respecified 10-item model without Item 24 was fitted. Detailed results, including statistical parameters of the multiple-groups CFA models, are reported in Paper III.

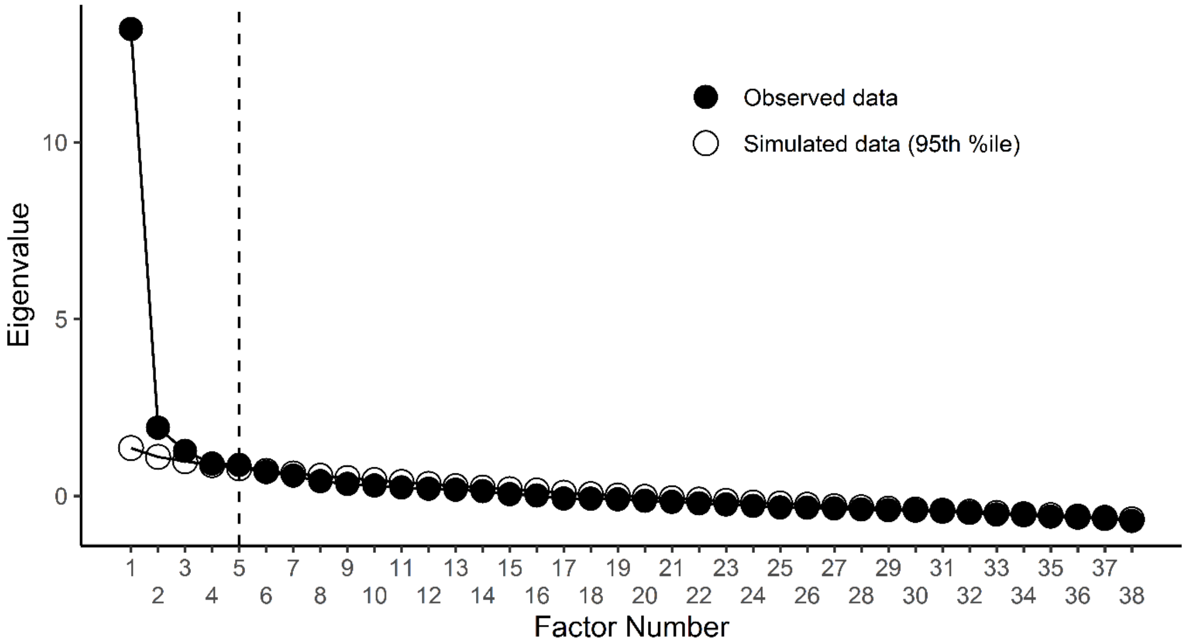
In summary, Impact of Fatigue (10 items) was fully invariant across groups. Results on Signs and Direct Consequences of Fatigue and Mental Fatigue supported partial metric invariance. The factor loadings of Item 7 and 3, respectively, were weaker among respondents in the stroke unit. Regarding Physical Fatigue, evidence supported partial threshold invariance. The second threshold of Items 9 and 14 varied between groups. In the following step, metric invariance (equal factor loadings) was supported.

Factorial Structure

Research Objective 4. In EFA, five factors were selected based on parallel analysis, although three- and four-factor solutions also appeared reasonable by visual inspection of the scree plot (Figure 6). The five-factor model accounted for 51% of observed variance (Table 8). Factor loadings, communalities, and item complexity values are provided in Table 9. Five items did not load substantially (≥ .40) on any factor, and eleven items cross-loaded on multiple factors. Eight items had complexity values above 3.00, indicating that at least three factors were required to account for item variation.

Figure 6

Parallel Analysis Scree Plot of Dutch Multifactor Fatigue Scale–Danish



Note. $N = 149$. Extraction method was principal axis factoring of polychoric correlation matrices. Observed eigenvalues were compared against the 95th percentile of eigenvalues for 100 random normal matrices of equal sample size.

Table 8

Eigenvalues From Exploratory Factor Analysis of Dutch Multifactor Fatigue Scale–Danish

Factor	Eigenvalue	% of variance	Cumulative %
1	6.22	16	16
2	5.13	14	30
3	3.68	10	40
4	2.39	6	46
5	1.83	5	51

Note. *N* = 149. Extraction method was principal axis factoring of the polychoric correlation matrix with a varimax rotation. Root mean square error of approximation = 0.112, 90% CI [0.106, 0.119], Tucker-Lewis index = 0.608, mean item complexity = 2.3.

Table 9

Item Statistics From Exploratory Factor Analysis of Dutch Multifactor Fatigue Scale–Danish

Item	Abbreviated content	Factor loading					h^2	Com
		1	2	3	4	5		
Impact of Fatigue								
13	Can be overcome	**.68**	.22			.19	**.56**	1.44
1	Often tired	**.64**	.11	.34	.14	.13	**.58**	1.80
6	Hinders doing things	**.58**	.22	**.43**		.33	**.68**	2.87
38	Suffer terribly	**.57**	.33	**.44**	.10		**.64**	2.60
26	Severe fatigue	**.53**	.31	**.41**	.23	.21	**.64**	3.42
20	Tired every day	**.52**	.27	.31	.19		.47	2.57
33	Affects whole life	**.52**	**.44**	**.46**		.25	**.74**	3.44
29	Most serious problem	**.48**	.11	**.52**			**.52**	2.11
22 [a]	Can easily get over	**.46**	.14	**.57**	.30	.20	**.68**	2.93
35	Can't go further	.23	**.61**	.32		.38	**.67**	2.63
24 [a]	Don't need to rest	.17	.24		.10	.27	.18	3.17
Signs and Direct Consequences of Fatigue								
21	React emotionally	.27	**.63**			-.15	**.50**	1.55
28	Say things I regret	.14	**.61**				.40	1.12
7	Emotional issues	.32	**.56**			.13	.45	1.80
31	Thinking/next day	.36	**.56**	.36		.19	**.62**	2.80
19	Induces headache		**.51**	.33	.14		.39	1.92
4	Fatigued in afternoon	**.60**	.25	.19	.13	.11	.48	1.76
15	Other people notice	**.44**	.22	.19	.21		.33	2.42
11 [a]	Recover easily	.38	.13	**.46**	.26	.25	**.51**	3.38
23	Letting thoughts go	.10	.34	.37		-.14	.29	2.54

Item	Abbreviated content	Factor loading					h^2	Com
		1	2	3	4	5		
Mental Fatigue								
37	Cannot think	.35	**.62**	.15		.36	**.66**	2.42
17	Stimulation	.30	**.54**			**.42**	**.57**	2.61
10	Thinking	.22	**.51**	.25		.17	.41	2.23
32	Make mistakes	**.56**	.39			.16	**.50**	1.99
27	Concentrating	**.69**	.36	.18		.31	**.74**	2.13
34	Complaints get worse	**.49**	**.42**	.35	-.22	.26	**.66**	3.87
3 [a]	Conversations	.29	.29	.18		.11	.22	3.10
Physical Fatigue								
9 [a]	Physical condition	.11	.10	.15	**.87**		**.80**	1.11
5 [a]	Physically fit			.12	**.75**		**.59**	1.08
18	Physical exertion	**.46**	.14		.25		.30	1.81
30	Little energy	**.47**	.24	**.48**	.32		**.60**	3.27
14 [a]	Wake up rested	.11		**.69**	.31		**.59**	1.45
25	Body aches	.10	.36	**.48**	.22	-.16	.45	2.69
Coping with Fatigue								
2 [a]	Plan to rest	-.13				**-.59**	.37	1.15
12	Finish tasks			-.11	-.35	-.29	.22	2.17
36	Get overtired	**.44**	**.51**	.22	.18	-.34	**.65**	3.46
8	Get tired out	**.41**	**.47**				.39	2.06
16 [a]	Avoid overtiredness	.26			.37		.22	2.09

Note. N = 149. Extraction method was principal axis factoring of the polychoric correlation matrix with a varimax rotation. Items are grouped according to the original factorial structure. Factor loadings below .10 are omitted. Factor loadings above .40 and communalities above .50 are in bold. h^2 = communality; Com = Hofmann's complexity index.

[a] Reverse scored.

5 Discussion

At this point, the reader has been introduced to numerous methodological procedures, qualitative syntheses, and statistical figures of the research comprised by this thesis. In this chapter, each of the two research projects is discussed consecutively in relation to respective aims of the thesis, previous research, and clinical implications. Next, joint implications of the research are discussed in context of tailored treatment. This is followed by a discussion of methodological considerations, leading to considerations on future perspectives.

5.1 Aim 1: A Treatment Model of Energy Management

The Treatment Model Project aimed at translating practice-based understandings, knowledge, and routines of EM into a treatment model using the RTSS framework. This section discusses the EM model, including interpretations of case study results, implications of the treatment model, and recommendations for clinical practice and future research. Findings are also discussed in Paper I, and this section extends on that discussion.

Interpretations of Main Results

A treatment model of EM was developed and refined based on established practices in fatigue management, specifying five main treatment components: (a) Knowledge and Understanding of Fatigue, (b) Interoceptive Attention of Fatigue, (c) Acceptance of Fatigue, (d) Activity Management, and (e) Self-Management of Fatigue. At this stage, the model reflects routine practice at a specialized brain injury rehabilitation center in Denmark, and it need not be exhaustive in its description of EM. However, themes emerging in case analysis align well with previous research in fatigue management (e.g., Teng et al., 2022). For example, a qualitative study synthesized how individuals with stroke (n = 20) and caregivers (n = 8) manage fatigue in everyday life, which included accepting fatigue, planning activities, keeping a diary, and using relaxation techniques (Ablewhite, Nouri, et al., 2022). Other research report that clinicians provide education about fatigue, strategies for activity management, and fatigue/activity diaries (Ablewhite, Condon, et al., 2022; Drummond et al., 2022). Overall, components of the EM model resemble themes in previous research. Although the model is based on practice at a specific site, this consistency is encouraging to the generalizability of the results underpinning the model.

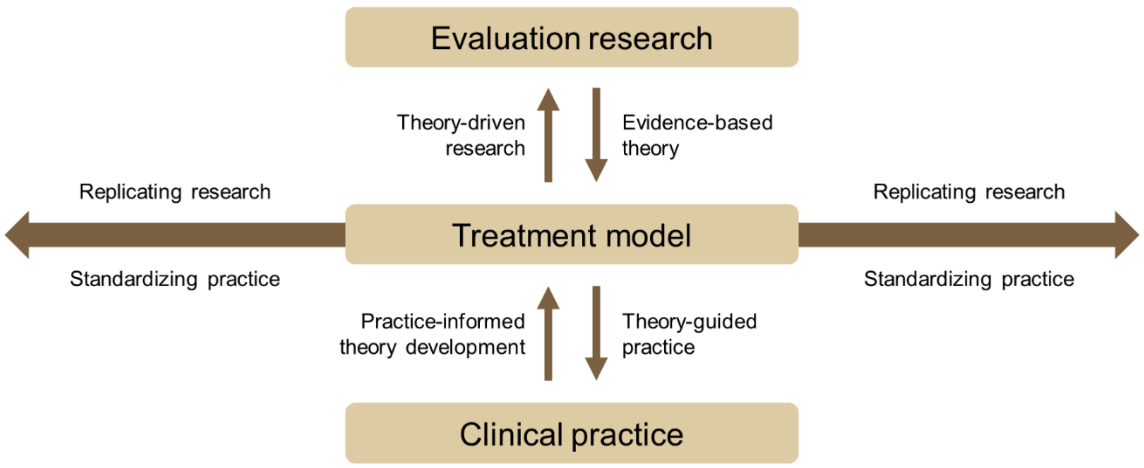
Quantitative data were collected in the case study in order to promote transferability of findings by describing case characteristics and trajectories in rehabilitation. Considerations are needed in the interpretation of these data. The study is not able to support inferences of efficacy due to the naturalistic research design (e.g., single-group, pre-post, non-experimental design with a small sample). As such, variations in self-report outcomes (or lack hereof) may be due to measurement error or confounders such as spontaneous recovery, awareness of one's condition, distress related to workload, vocational status, etc. The study was not designed to assess efficacy, and results are not to be interpreted in this regard. Further, the model is strictly concerned with treatments for reducing the impact of (persistent) fatigue and does not consider other treatments designed to reduce fatigue (e.g., treating potential causes or modifiable contributors to fatigue). Thus, it provides standard descriptions of some aspects of clinical practice, which need to be integrated among other treatments for fatigue.

Implications of Findings

Theory-Driven Evaluation Research. The EM model does not make claims about efficacy of treatment components. But it specifies these components in a standardized manner and posits hypotheses to be tested in empirical research. This is a first step in a line of work to facilitate evidence-based practice in fatigue management (Figure 7), as a RTSS-based description of treatment may guide evaluation research and dissemination of findings (van Stan et al., 2019). The EM model enables testing and refinement of hypothesized treatment components that are currently being practiced in lack of evidence. Contesting treatment theories in empirical research may indicate a need for revising the model and adapting routine practice. Perhaps some ingredients need to be discarded or modified, while other components of EM may be neglected, misspecified, or disorganized. Translating such findings into clinical practice will be essential to advance care. If evidence support efficacy of treatment components, then the EM model facilitates standardization, replication, and dissemination of this treatment program (Figure 7). Further, RTSS provides a shared language to promote interdisciplinary communication, training, and education (Zanca et al., 2019).

Figure 7

Facilitation of Evidence-Based Practice Using Treatment Models



Note. The figure illustrates how a treatment model may facilitate translation between research and practice (vertical plane) and dissemination of knowledge (horizontal plane).

Clinical Decision-Making in Tailored Treatment. The experience of fatigue is heterogeneous, and treatment encompasses multiple components for interrelated problems. As guidelines and standard descriptions of practice are lacking, clinicians rely primarily on individual experience and knowledge when managing fatigue following ABI (Drummond et al., 2022; Riley, 2017). Consequently, practice is prone to vary across service providers, and quality of care may depend on the training, knowledge, and experience of individual practitioners. By specifying a set of theories linking ingredients with respective targets in a systematic fashion, the EM model may facilitate shared terminology, accentuate underpinning theories, and provide well-defined standards of practice across disciplines.

To remind the reader, RTSS organizes treatment components in three mutually exclusive groups: (a) Organ Functions, (b) Skills and Habits, and (c) Representations (Hart et al., 2019). The components of EM were associated with two of the three treatment groups, namely Skills and Habits and Representations. Treatment groups cue clinical reasoning about how intended changes in functioning can be induced. For example, targets in the Skills and Habits group (e.g., forming a habit of planning activities according to anticipated energy levels) require the clinician to facilitate repeated practice to improve skills and form habits. Likewise, targets in the Representations group (e.g., enhanced knowledge of triggers of fatigue symptoms) require the clinician to facilitate information processing of some material to influence understandings, attitudes, etc. As EM is concerned with promoting self-management, no target was specified in the Organ Functions group.

Thus, the RTSS framework encourages clinicians to articulate how targets may be achieved by therapeutic actions (Zanca et al., 2019), and the characterization of components guides deliberate planning of tailored treatment. By assisting clinical reasoning processes in treatment planning, the EM model is flexible, dynamic, and responsive to individual needs while providing standard descriptions of treatment components. This approach stands in contrast to “one-size-fits-all” treatment manuals, comprising a defined number of sessions in fixed order. In practice, they may be difficult or undesirable to adhere to due to the diverse needs of the clinical population and the varying contextual contingencies. Considering the complexity and need for adaptation in management of fatigue (e.g., the diverse nature and impact of fatigue, interacting components, multiple disciplines, etc.), it seems promising to support clinical practice using a flexible treatment model based on the RTSS framework.

Recommendations

Rehabilitation of fatigue is hampered by the lack of evidence-based treatment, standard descriptions, and clinical guidelines. The EM model specifies components in fatigue management, and considering the prospects of the model, it is recommended as a tool to support tailoring of treatment in clinical practice. Further, contesting and revising treatment theories in the model is encouraged for future research.

Deriving the model from routine practice may ease implementation and narrow the gap between research and practice. However, clinical utility of the model and efficacy of its treatment components have not been established. Thus, research is needed to identify any implementation issues, especially since the accurate application of the model requires a basic understanding of the RTSS framework. Implementation is crucial for the effectiveness of interventions, and several frameworks are available to facilitate implementation processes (see, e.g., Pfadenhauer et al., 2017). Further, process evaluations (nested within a randomized controlled trial) are a useful research design for testing implementation processes and treatment theories (Moore et al., 2015). In this context, the targets of a treatment model may inform the selection of outcome measures in order to assess efficacy of specific treatment components (van Stan et al., 2019). For example, outcomes should include measures of knowledge and understanding of fatigue, acceptance of fatigue, skills and habits in activity management, etc.

5.2 Aim 2: Validity of Dutch Multifactor Fatigue Scale

The main objective of the Validation Project was to evaluate test validity of DMFS–D in relation to the factorial structure and construct theory proposed by Visser-Keizer et al. (2015). Evidence of validity was evaluated based on response processes and internal structures of DMFS–D. First, inferences regarding the properties of original subscales are synthesized based on the evidence collected. Next, implications of the findings are discussed followed by recommendations regarding DMFS–D.

Interpretations of Main Results

Of the five original subscales, Impact of Fatigue, Signs and Direct Consequences of Fatigue, and Mental Fatigue performed adequately. Overall, respondents interpreted items as expected based on construct theory. The internal structure of these subscales supported assumptions of unidimensionality, and they were at least partially invariant across early and late rehabilitation settings. Contrarily, unidimensionality was not supported for Coping with Fatigue and Physical Fatigue. Items on Coping with Fatigue elicited response processes that were congruent with the intended construct, but the internal structure of items did not indicate a unitary common factor. Regarding Physical Fatigue, substantive evidence based on both response processes and internal structure indicated an issue of local dependency, indicating that two items measure a distinct concept in addition to the latent variable. Consequently, the assumption of unidimensionality is compromised.

Regarding the factorial structure of all 38 items, the original factor solution was not reproduced sufficiently. The optimal number of factors was equal to the original scale. However, the structure of the five factors was divergent, and none of the original subscales were replicated. One factor (Factor 4) mainly accounted for covariance among the two locally dependent items (5 and 9), and each of the remaining factors explained covariance among items distributed across the original subscales. In addition, eleven items (29%) were cross-loading on multiple factors. Thus, results indicate that the constructs of the four original subscales, which are purported to measure aspects of fatigue, are not clearly distinct. Possibly, a general factor of fatigue may blur the lines between more subtle aspects addressed by subgroups of items. Future research may consider evaluating hierarchical or bi-factor models to address this hypothesis and identify items that are important to the unique aspects of fatigue that each subscale intends to measure.

In summary, while this study challenges the original factorial structure of DMFS, results support validity of three of the original subscales. However, the extent to which these exact subscale compositions measure distinct aspects of fatigue is questionable. Meanwhile, results support the claim of multidimensionality of the total scale, and a single sumscore of all items should not be used. The optimal structure of DMFS is yet to be determined, including whether additional items need to be eliminated.

Comparisons With Prior Results

Results are not consistent with prior results of Visser-Keizer et al. (2015). However, this is not surprising for at least three reasons. First, the factorial structure of DMFS was derived from a concept scale without confirming the results in an independent sample. In other words, the design of the final DMFS was fitted to the development sample. Thus, item selection and the original structure may represent characteristics of the initial sample in addition to characteristics of the population (i.e., chance effects), especially considering the relatively small sample (N = 134) for factor analysis. Consequently, a second sample may not replicate results of the development sample (Cappelleri et al., 2014).

Second, items were translated from English into Danish, and although using a back-translation procedure to eliminate translation errors and promote adequacy of the translation, the phrasing of items will not be completely equivalent across languages (Sechrest et al., 1972). A fitting example is the lack of an equivalent to the term “fatigue” in Danish. The Danish term *træthed*, which is closely related to “tiredness”, is frequently used in translations, although the terms are not conceptually equivalent. The inherent discrepancies across languages in addition to cultural variations may be a source of inconsistency in results. Especially considering the original version first was translated into English before being translated into Danish.

Third, sampling procedures differed across studies in numerous ways (settings, data collectors, eligibility criteria, etc.), resulting in diverging sample characteristics and target populations. In contrast to Visser-Keizer et al. (2015), this study included inpatients shortly after stroke onset, constituting a third of the sample, and excluded mild TBI, which constituted 16% of Visser-Keizer et al.’s (2015) sample. These variations may also account for inconsistencies, especially since non-equivalent items performed worse among inpatients.

In summary, any of the factors above may affect the outcome of results and contribute to inconsistencies between the present study and the original validation by Visser-Keizer et al. (2015). This challenges inferences regarding implications and wider generalizations.

Implications and Recommendations

Implications are primarily considered in a Danish context. Violations of unidimensionality for Coping with Fatigue and Physical of Fatigue imply that sumscores are not readily interpreted, because items do not reflect unitary constructs. Thus, in lack of further evidence, it is generally not recommended to use these subscale scores based on present findings. However, the items may still provide a qualitative account of the aspects addressed by the items. The remaining three subscales (i.e., Impact of Fatigue, Signs and Direct Consequences of Fatigue, and Mental Fatigue) are recommended for measuring fatigue, and they may be superior to other alternatives in a Danish context depending on the specific purpose of assessment. Although DMFS was developed to assess fatigue in late stages of ABI (> 6 months), present findings support use of these subscales in early rehabilitation settings as well. A few items were non-equivalent across groups, however, performing worse among inpatients. But the extent of the problems was not a concern for obtaining comparable test results in early and late rehabilitation settings.

Comparison of Fatigue Scales. In contrast to existing fatigue scales, DMFS was specifically developed for ABI, and to the author's knowledge, it is currently the most rigorously validated fatigue scale in a Danish ABI population. On this basis, DMFS–D is generally recommended for measurement of fatigue following ABI compared to other scales such as Multidimensional Fatigue Inventory (Smets et al., 1995), Fatigue Severity Scale (Krupp et al., 1989), or Mental Fatigue Scale (Johansson et al., 2010), in which relevant evidence of validity is sparse. However, test validity is not inherent to the scale, and the appraisal of scales relies on the proposed uses (AERA et al., 2014). For example, Multidimensional Fatigue Inventory has reference data for the general Danish population (see Boter et al., 2014; Norup et al., 2019; Watt et al., 2000), which can be useful for specific interpretations of test scores. In this respect, no Danish reference data on healthy individuals exist for DMFS–D, although Dutch reference data can be used with caution. In addition, evidence is lacking for specific uses of DMFS–D such as test-retest reliability and responsiveness to change. Unidimensionality is a central assumption of any scale score interpretation, and the evidence regarding unidimensionality is generally strong for DMFS–D compared to other fatigue scales in Denmark.

Revisions to the Danish Translation. The potential problems identified in the present validation of DMFS–D are summarized in Table 10. The word "potential" is intentional as the table summarizes all evidence indicating a potential problem regardless of severity of that problem or weight of the evidence. Based on the findings, it is recommended to rephrase items 24 and 29 in the Danish translation (suggested revisions are provided in Appendix D).

These items can be revised while maintaining conceptual consistency with the original DMFS. Any means to accommodate the remaining potential problems would cause DMFS–D to diverge from the original version, which is not desirable. Thus, those problems may be pertinent to the original version, and research is recommended in other versions of DMFS to determine whether general revisions are needed. Except the violations of unidimensionality, the remaining potential problems in Table 10 are not deemed critical to the utility of DMFS–D.

Table 10

Potential Problems Identified in Validation of Dutch Multifactor Fatigue Scale–Danish

No.	Subscale	Item	Source of evidence	Description
1	IF	24	Response processes	Syntactic complexity in phrasing
	IF	24	Internal structure	Poor indicator of the latent variable
2	IF	29	Response processes	Vague term (“complaints”)
3	SC	7	Response processes	Ambiguous term (“emotional issues”)
4	SC	15	Response processes	Ambiguous term (“other people”)
5	MF	3	Response processes	Ambiguous term (“conversations”)
	MF	3	Internal structure	Relatively poor item performance
6	MF	17	Response processes	Double-barreled (“activity or noise”)
7	MF	34	Response processes	≥ 50 % non-congruent with construct theory
8	PF	-	Internal structure	Violation of unidimensionality assumption
9	PF	5+9	Internal structure	Local dependency
	PF	5+9	Response processes	≥ 50 % non-congruent with construct theory
10	PF	14	Response processes	Presupposition (“a good night’s sleep”)
11	PF	25	Response processes	≥ 50 % non-congruent with construct theory
12	PF	30	Response processes	≥ 50 % non-congruent with construct theory
13	CF	-	Internal structure	Violation of unidimensionality assumption

Note. IF = Impact of Fatigue; SC = Signs and Direct Consequences of Fatigue; MF = Mental Fatigue; PF = Physical Fatigue; CF = Coping with Fatigue.

Further validation. As such, DMFS–D is recommended, while concerns are addressed regarding some items and the factorial structure. Thus, further validation is justified to facilitate interpretations of test scores, e.g.: (a) determining the optimal factorial structure, (b) evaluating additional measurement properties, (c) collecting Danish reference data, (d) reworking Coping with Fatigue and/or Physical Fatigue, and (e) constructing a short scale to limit response burden, e.g., using item response theory.

5.3 Joint Implications for Tailored Treatment of Fatigue

This section discusses the clinical utility of DMFS as a preassessment tool for targeting components of EM to individual needs. Considering the ambiguous factorial structure of DMFS, the utility of original subscales will not be addressed. Further, concerns specific to DMFS and the EM model, respectively, were addressed in previous sections and are not repeated in the following discussion.

DMFS addresses several aspects of fatigue following ABI, including emotional, cognitive, and physical factors and strategies for management. This detailed and multifaceted information may be useful to clinicians identifying specific targets for treatment. In this context, DMFS may be advantageous compared to unidimensional scales such as Fatigue Severity Scale (Krupp et al., 1989) or Mental Fatigue Scale (Johansson et al., 2010), providing a narrower account of fatigue. Nevertheless, one may argue that DMFS provides restricted information for tailoring components of EM due to the nature of the treatment targets. Targets of the model include both skills, habits, knowledge, and attitudes. Ideally, skills and habits are assessed by observing performance, knowledge is evaluated using quizzes, and attitudes can be measured using rating scales. In this respect, DMFS is a rating scale addressing attitudes concerning fatigue. DMFS does not provide a direct measure of skills, habits, or knowledge. It may, at best, address respondents' attitudes toward their skills, habits, and knowledge of fatigue.

Thus, a complete pre-assessment for EM requires multiple methods, e.g., rating scales, observations, clinical interviews, performance tests, etc. For example, a quiz about fatigue may be useful for measuring targets within the EM component Knowledge and Understanding of Fatigue. A quiz may evaluate general knowledge about the nature of fatigue, e.g., signs of fatigue, triggers of fatigue, consequences of fatigue, etc. Based on quiz results, clinicians may evaluate the need for enhancing knowledge of fatigue, e.g., by initiating educational ingredients to facilitate desired information processing. However, as the nature of fatigue varies across individuals, all aspects of the quiz may not apply to everyone. Nevertheless, general knowledge of fatigue may facilitate the process of learning about one's own condition by comparing this information to subjective experiences.

In connection with arguments above, the outcome measures included in the case study may not be adequate to evaluate treatment theories of the EM model. To remind the reader, RTSS distinguishes between targets and aims, which are concerns of treatment theory and enablement theory, respectively. DMFS addresses some aspects of direct targets in EM but may also address more distal aims of treatment such as impact of fatigue. Impact relies on several factors in addition to the therapeutic processes in treatment. For example, treatment may be successful in enhancing knowledge of fatigue, improving interoceptive attention, and forming desired habits in daily life. Nevertheless, fatigue may continue to exert a large impact due to additional factors not addressed in treatment. Treatment may even successfully improve awareness of limitations posed by fatigue, potentially leading to greater perceived impact of fatigue. Thus, standardized outcomes need to be interpreted cautiously with respect to treatment theory, and additional outcomes tailored to specific targets may be required to test treatment theories adequately.

5.4 Methodological Considerations

Strengths and limitations of the research designs are discussed with respect to internal validity (credibility of inferences) and external validity (generalizability of inferences). Brief accounts of study limitations are provided in respective papers. Thus, this section discusses general strengths and limitations across the studies and central considerations requiring elaboration.

Concerns Regarding the Treatment Model Project

Methodology. As EM is established in routine practice, the aim of the Treatment Model Project was to develop a theoretical model based on practice-based understandings. Case study methodology is suitable for in-depth and multi-faceted investigations of "contemporary phenomena within its real-life context" (Crowe et al., 2011, p. 1). Thus, the naturalistic design of the case study was preferred as it is useful for exploring stakeholders' experiences of a rehabilitation program to generate a theoretical account of how treatment components work. Further, co-producing with stakeholders is valuable to elicit an accurate understanding of existing treatments not yet well described (Evans et al., 2015). In sum, the methods are deemed appropriate for pursuing the objectives of this project.

Study Design and Data Triangulation. Utilizing both co-production workshops and in-depth case studies provided a comprehensive account of EM. Several data collection methods were used to reflect the views of multiple stakeholders. As such, the co-production workshops provided rich detail on the ingredients of EM, while retrospective interviews illuminated the nature of outcomes and hypothesized mechanisms in treatment. Multiple data sources enabled triangulation (credibility assessment) by verifying information across interviews, log entries, and questionnaires. However, additional measures and other decisions regarding the research design could have improved the study. For example, involving service users in the co-production process or involving clinicians in the revisions of the model could have provided additional perspectives on EM to support credibility of the model. In particular, direct observations in treatment sessions or focused interviews immediately following sessions would have been favorable.

Additional means to ensure reliability of data analysis could have been carried out, e.g., inviting participants to review transcripts and the final synthesis of interviews, especially since one researcher (F.D.) conducted the majority of formal analysis. However, all transcripts and coding were reviewed by another researcher (T.S.) to verify accuracy, reduce risk of bias, and eliminate misinterpretations and omissions of relevant information. Further, codes were thoroughly organized in an iterative process during second-cycle coding and systematically applied to a conceptual framework (RTSS) supporting the analysis.

Conceptual Framework. A prominent strength of the project was the utilization of a theory-driven framework of treatment, namely RTSS. RTSS not only provides a framework of treatment theory but also a heuristic tool for specifying treatments. As the objective was to develop a treatment model, this framework improved the research design considerably. F.D. and T.S. were both familiar with the framework, and instructions were provided to clinicians making log entries. However, additional procedures could have been realized to ensure full implementation of RTSS in data collection. Applying RTSS terms accurately requires extensive practice, and several log entries were not compatible with RTSS. Thus, quality of this data source was somewhat compromised. Nevertheless, log entries were valuable in data triangulation, e.g., confirming information about contents and sequence of treatment episodes, especially since log entries and interviews were conducted at different time points (concurrently versus retrospectively).

Threats Related to Data Collection. Service providers were repeatedly prompted to reflect upon practice by keeping a treatment log. Thus, the log potentially influenced routine practice of EM. Simply knowing one’s practice is being evaluated may affect behavior, and self-report data may be susceptible to social-desirability bias. This risk concerns both log entries, interviews, and questionnaires. For example, service providers may be prone to report their intentions rather than actual practice. Further, responding may be unconsciously biased or inaccurate in order to appear in a favorable manner, especially since service providers and researchers knew each other (colleagues) as blinding was infeasible. Including the perspectives of service users was an important mean to assess and minimize this risk through triangulation. However, service users were also prompted weekly to evaluate perceived energy levels, potentially affecting treatment and recovery processes. Further, they built social relationships with service providers during rehabilitation, potentially affecting opinions about treatment in retrospect interviews. However, these risks are difficult to avoid entirely in naturalistic designs, and data were analyzed critically. Further, the extent to which these factors potentially compromise accurate reporting of treatment components, specifically, is not considered to be of critical concern to the credibility of findings. For example, the risk of socially desirable responding would be of greater concern for inferences on efficacy.

Sampling Strategy. Participants were sampled prospectively to select five eligible individuals referred to vocational rehabilitation experiencing clinically significant fatigue. The criterion concerning fatigue was important to ensure that cases represent the construct of interest (i.e., practice of EM to reduce impact of fatigue). Although the case definition of fatigue (Lynch et al., 2007) was developed for stroke, it was deemed feasible for other types of ABI in consultation with the corresponding author to the original publication (G. Mead, personal communication, n.d.). Further, a criterion was defined regarding time since injury (3–24 months) to ensure that fatigue was relatively persistent (e.g., unrelated to hospitalization and acute care) yet not chronic in terms of management routines. Sampling was not designed to illustrate variations in practice, e.g., by selecting typical and deviant cases. Future research may investigate variations and contextual contingencies on the practice of EM.

Generalizability. The treatment model was developed based on routine practice at a single rehabilitation center in Denmark. However, practice may vary across sites, and the model may not represent other aspects of EM practiced elsewhere that may be important to improving self-management of fatigue. To facilitate applicability and transferability of findings, the rehabilitation center and participants were comprehensively described. The model is not considered finite, and further research contesting and refining propositions of the EM model is encouraged.

Five participants were enrolled, but one participant was withdrawn from the case study due to mental distress. Further, two individuals declined to participate due to lack of energy. Thus, the findings may underrepresent subgroups of the target population for the EM model. However, the entire target population was considered in co-production workshops, and the extent to which treatment components may vary across subgroups is uncertain.

Concerns Regarding the Validation Project

Research Designs. The Validation Project integrated multiple sources of validity evidence, including evidence based on response processes and internal structure. This mixed-methods approach enabled data triangulation, which strengthens credibility of inferences. For example, evidence of local dependency in Physical Fatigue was indicated in analyses of both response processes and internal structure. Further, each source of evidence illuminates distinct aspects of the validity argument. For example, analysis of response processes may indicate whether interpretations of items conform to construct theory, while analysis of internal structures may indicate whether relationships among items conform to assumptions of the intended construct (AERA et al., 2014). Further procedures could have been employed to illustrate additional aspects of DMFS, however. For instance, this project relied on classical test theory, while modern test theory could have provided other perspectives on item performance. However, these procedures (e.g., item response theory models) generally require larger samples with sufficient observations of each response category to provide reliable parameters.

Sample Size in Cognitive Interviewing. Cognitive interviewing is concerned with in-depth qualitative analysis to assess the substantive nature of response processes in a small sample of informants rather than quantifying the significance of issues in relation to population parameters (Willis, 2005). However, covert problems may be overlooked in small samples, and findings need to be interpreted in relation to characteristics of participants (provided in Paper II). For example, all participants were interviewed at least 10 months post-injury, and items may be interpreted differently shortly after injury.

Procedures in Cognitive Interviewing. The procedures of cognitive interviewing (e.g., think-aloud) are unusual to informants and may affect interpretative processes. For example, informants may reflect extensively upon the interpretation of items. It may help them comprehend otherwise difficult items, or it may cause confusion due to deliberate consideration of every word and phrase of the items. The standardized TSTI procedure was used to minimize the risk of contaminating natural response processes. For example, probing is done retrospectively after the informant has initially engaged with the questionnaire. In the first step, the informant only has to think aloud, while the researcher observes passively as to not affect response processes. However, the setting is inevitably artificial and experimental, which inherently poses a threat to the external validity of findings based on TSTI. This risk needs due consideration but is not deemed to cause a critical concern regarding credibility.

Sample Size in Factor Analysis. Initially, target sample size was determined for EFA using rules of thumb. However, requisite sample size for factor analysis depends on numerous factors related to the data and the model (Brown, 2015, Chapter 10; Kyriazos, 2018). Ideally, target sample size was determined using a simulation approach to ensure sufficient power and accurate parameter estimates and fit statistics (Kyriazos, 2018). Although N = 149 is generally to be considered small for CFA, this size is not necessarily inadequate considering the models specified. In particular, reducing model complexity by investigating subscales separately and using WLSMV estimation instead of WLS or maximum likelihood ease requirements on sample size (Kyriazos, 2018). Nevertheless, the reliability of parameter estimates and fit statistics is uncertain, and results need to be interpreted cautiously. This concern is stressed regarding results on measurement invariance, in which parameters are estimated simultaneously in two sub-groups of the sample.

Procedures in Factor Analysis. Moving from the CFA to the EFA framework is contradictory to most textbook examples of factor analysis (e.g., Brown, 2015). However, this sequence of analytic steps was intentional, as the main objective was to evaluate DMFS–D based on the original structure proposed by Visser-Keizer et al. (2015). Thus, the original subscales were evaluated using CFA, and EFA was then applied to explore interrelationships among items across subscales. CFA was not used to examine the entire scale, as a larger sample would be needed for a model this complex. One may argue that proceeding to CFA is premature considering the sparse evidence on the original factorial structure. However, the proposed structure does constitute prior hypotheses based on EFA, which are testable using CFA. The objective was not to propose a competing structure of DMFS, but findings do contest the original structure and indicate a need for evaluating the composition of subscales exploratively in future research.

Finally, multiple procedures exist for factor selection in EFA without a gold standard, and they may provide conflicting results. This study relied on parallel analysis, which is a recommended procedure to determine the optimal number of factors. However, it needs to be recognized that other procedures may had indicated other solutions.

General Concerns Related to External Validity

Participants in both the case study (Paper I) and cognitive interviewing (Paper II) all had stroke, and individuals with other types of ABI were not represented. Further, 92.6% of participants in the psychometrics study (Paper III) had stroke. Thus, specific subgroups of the

ABI population were not well represented, especially in Papers I and II, and caution needs to be exercised when generalizing results to subgroups, e.g., individuals with TBI. However, the ABI population was intentionally defined as one target group, assuming comparability among the patients regarding assessment and treatment of fatigue despite diverse injury mechanisms. Research indicate that the experience of fatigue may differ across health conditions (Eilertsen et al., 2015; Whitehead et al., 2016). But no evidence yet suggest that the nature and impact of fatigue differ substantially across brain injury populations. Particularly, treatment components of EM are not directed at specific disease mechanisms contributing to fatigue but the mechanisms by which fatigue interferes with everyday life. Several treatments of fatigue, including EM, are used across numerous health conditions, and mechanisms in fatigue management are potentially transdiagnostic (Hulme et al., 2018).

5.5 Perspectives for Rehabilitation of Fatigue

Three topics for future research are discussed, including (a) management of contributing factors in clinical practice, (b) the need for disease-specific versus generic fatigue scales, and (c) the prospects of alternative approaches to assessment of fatigue.

Grasping the Complexity of Fatigue in Clinical Practice

As fatigue is a non-specific symptom associated with numerous health conditions, the potential causes and contributors to fatigue are manyfold. Accordingly, potential treatments are extensive and wide-ranging, e.g., adjusting medications, managing extensive worries, encouraging physical activity, etc. Considering predisposing and contributing factors is essential in treatment planning, and managing these factors may alleviate the severity and impact of fatigue. However, the interplay of fatigue and associated factors is complex. An interdisciplinary and transdiagnostic framework of modifiable contributors to fatigue may be a valuable tool for clinical practice (Aarnes et al., 2020). De Groot et al. (2003) proposes a model for assessment and intervention of post-stroke fatigue, including the identification of predisposing factors to guide treatment planning. In this context, the EM model constitutes one set of treatments to promote self-management, and it needs to be supplemented by other initiatives in clinical practice.

Thus, promising avenues for future research include: (a) mapping contributing factors to fatigue, (b) validating reliable indicators of these factors, (c) specifying treatments for contributing factors, (d) synthesizing evidence on efficacy and clinical utility of these treatments, and (e) developing a comprehensive model guiding planning of tailored treatment for reducing the severity and impact of fatigue. The model may need to distinguish between more versus less essential contributors and transdiagnostic versus disease-specific components. For example, some contributing factors may be independent of the underlying health condition, while others may be prominent in certain diseases.

Disease-Specific Versus Generic Fatigue Scales

The vast amount of fatigue scales without a gold standard hampers comparative research and scientific progress. In this context, it may seem inappropriate to validate and advocate a new disease-specific scale of fatigue such as DMFS. Hjollund et al. (2007) posit that disease-specific scales are not needed because fatigue is a non-specific symptom. Further, one may argue that generic scales that work across conditions are needed such as the Fatigue Severity Scale (Krupp et al., 1989) or the Multidimensional Fatigue Inventory (Smets et al., 1995). An advantage of generic scales is the accumulation of validity evidence across populations, leading to fewer but more robust measures of fatigue enabling transdiagnostic comparisons. However, using a scale for another purpose than that for which it was originally developed needs justification (AERA et al., 2014). At least two concerns can be raised about using generic fatigue scales in ABI populations without credible evidence of validity.

First, there is a risk of conflating fatigue scores with the effects of neurological sequelae. Fatigue scales frequently address fatigue in terms of impact on functioning, but the same aspects of functioning may also be affected by neurological sequelae (Mead et al., 2007; Tyson & Brown, 2014). On the Multidimensional Fatigue Inventory, for example, items on the Mental Fatigue subscale address difficulties concentrating, e.g.: “It takes a lot of effort to concentrate on things” or “[m]y thoughts easily wander” (Smets et al., 1995). Likewise, items on Physical Fatigue address physical functioning, e.g.: “Physically, I feel only able to do a little” (Smets et al., 1995). Cognitive deficits and physical impairments are common consequences of ABI, and respondents can have difficulties distinguishing the effect of these deficits from the effect of fatigue (Mead et al., 2007). In other words, this is a problem of construct-irrelevant variance (or construct contamination), i.e., test scores are biased by extraneous processes to the intended construct (AERA et al., 2014). The risk of this problem is emphasized for generic scales (as illustrated above), as the effects of neurological deficits are not considered and accounted for in scale development.

Second, a problem has to do with the nature of fatigue in ABI versus other diseases. The use of generic scales presupposes that the construct is similar across conditions. However, if the nature of fatigue varies by condition, there is a risk that the content of generic scales will not capture distinct aspects that may be important to the experience of fatigue following ABI. This is a problem of construct underrepresentation (or construct deficiency), i.e., test scores fail to measure important aspects of the intended construct (AERA et al., 2014). Notably, previous research identified variations in the nature of fatigue across long-term conditions (Eilertsen et al., 2015; Whitehead et al., 2016). In contrast to other health conditions, the experience of fatigue among individuals with stroke was characterized by symptom fluctuations and increased sensitivity to stress (Eilertsen et al., 2015). However, the implications of these findings for the generalizability of the construct(s) measured by fatigue scales are unclear and require research dedicated to this question. Thus, current evidence does not justify the use of generic scales, nor does it demonstrate the need for using disease-specific scales. However, previous research motivates concerns about using generic scales without considering these limitations.

In that respect, future research is recommended to investigate the extent to which neurological sequelae affect reasoning processes and item performance for fatigue scales. This question can be investigated by comparing sub-groups of respondents, e.g., with versus without impairments such as hemiparesis, cognitive deficits, etc. Multiple methods can be utilized in this endeavor, including cognitive interviewing (to compare response processes across groups), factor analysis (to test measurement invariance across groups), or item response theory models (to test differential item functioning across groups). This research will contribute to either (a) establish the need for disease-specific scales by demonstrating the superiority of these over generic scales, (b) justify the use of generic scales by rejecting transdiagnostic problems, or (c) cease the use of flawed generic scales in ABI by demonstrating group-specific measurement problems.

Alternative Approaches to Assessment of Fatigue

Much work has been devoted to the development of standardized questionnaires of fatigue. This thesis illustrates strengths and limitations of these scales, using DMFS as an example, in relation to the conceptual issues of fatigue. Questionnaires are retrospective and summative in nature, and they may not adequately capture the diurnal variations and interactive nature of fatigue as it fluctuates in everyday living. Considering these limitations, more attention needs to be directed to alternative approaches to assessment of fatigue. In clinical settings, fatigue/activity diaries are commonly used to assess symptom fluctuations and associations with contextual factors (Ablewhite, Condon, et al., 2022; Drummond et al., 2022). This approach offers a potential solution to some of the limitations of fatigue scales, but standardized and validated methods are needed. Lenaert et al. (2019) demonstrated feasibility of a structured diary method to assess symptoms of post-stroke fatigue momentarily during the day using a mobile device. Subsequent results indicated that this instrument provides distinct information about the nature of fatigue compared to a questionnaire, i.e., the Fatigue Severity Scale (Lenaert et al., 2020). Thus, structured diary methods are a promising alternative (or addition) to retrospective measures, providing to a more accurate, comprehensive, and ecologically valid account of daily patterns in fatigue and contextual influences. However, more work is needed to demonstrate the validity and clinical utility of such measures.

A parallel issue concerns the categorization of clinically significant fatigue. Fatigue scales are frequently used with more or less arbitrary cut-off scores to categorize subjects as fatigued versus non-fatigued, usually without sound justification of how the cut-off was defined. A promising alternative to this approach is the use of structured clinical interviews coupled with a set of criteria based on a definition of clinically significant fatigue. The post-stroke case definition, that was employed in this thesis, is a promising example of this approach (see Lynch et al., 2007). However, limited research has been conducted on this instrument, and more work is needed to establish clinical utility and ensure construct validity, inter-rater agreement, etc. A well-defined case definition may provide a gold standard in future validation of cut-off scores in lack of objective indicators of fatigue.

6 Conclusions

Fatigue is a common and debilitating condition following ABI, posing complex challenges to rehabilitation. This thesis set out to address specific issues related to treatment and assessment of fatigue. Two research projects pursued two respective aims of the thesis: (a) to define a treatment model of EM based on routine practice in rehabilitation of ABI, and (b) to evaluate test validity of DMFS for measuring aspects of fatigue following ABI.

Although EM is widely practiced for promoting self-management of fatigue, clinical guidelines and evidence of efficacy is lacking for ABI populations. In this work, a treatment model of EM was derived from in-depth analyses of routine practice and was specified using a systematic framework, namely RTSS. The model delineates treatment components and articulates theories of a complex and widespread interdisciplinary approach in rehabilitation of fatigue. The systematic descriptions of EM may guide clinical decision-making in person-centered rehabilitation and enable theory-driven evaluation research. As such, the model may ease translation between practice and research and facilitate knowledge dissemination to promote evidence-based practice. Successful implementation may provide shared terminology across disciplines and standards of practice across service providers. However, efficacy of treatment components and clinical utility of the model need to be determined in future research. Adaptations and revisions to the model are anticipated in this process. Further, the model characterizes a confined set of treatments for fatigue, which need to be integrated with other initiatives in clinical practice. In consideration of these limitations, the model addresses key issues in rehabilitation of fatigue, and further work is encouraged to implement and refine the model in clinical practice and research.

Treatment components in rehabilitation of fatigue need to be tailored to individual needs. DMFS is a promising scale to assist treatment planning as it provides a multifaceted account of fatigue following ABI. Based on a multi-center study, this thesis integrated validity evidence based on response processes and internal structures to evaluate the Danish translation of DMFS. Of the five original subscales, three are recommended for measuring fatigue in both early and late rehabilitation settings, namely Impact of Fatigue, Signs and Direct Consequences of Fatigue, and Mental Fatigue. The assumption of unidimensionality was violated for the remaining two subscales, Physical Fatigue and Coping with Fatigue, which compromises interpretability of sumscores. Although just three out of five subscales are recommended, DMFS–D has advantages compared to existing scales available in Denmark and may be preferable in clinical applications depending on the purpose of assessment. However, the optimal composition of subscales needs to be determined in future research, and potential modifications to individual items need consideration. Specifically, this thesis recommends two item revisions to DMFS–D to mitigate translational issues. Overall, findings provide sound evidence on measurement properties of DMFS to support accurate interpretations of test scores. Despite limitations, DMFS provides a promising alternative to existing fatigue scales for measuring multifaceted aspects of fatigue.

Overall, this thesis contributes to the scientific progress in developing and evaluating sound methods for treatment and assessment of fatigue following ABI. DMFS may be valuable in targeting some components of EM but needs to be accompanied by additional measures to provide a full pre-assessment. The original research, the conceptual implications, and the future perspectives of this work may help underpin clinical practice and future research for the benefit of users of rehabilitation services and the larger society.

7 References

Aarnes, R., Stubberud, J., & Lerdal, A. (2020). A literature review of factors associated with fatigue after stroke and a proposal for a framework for clinical utility. *Neuropsychol Rehabil*, *30*(8), 1449–1476. https://doi.org/10.1080/09602011.2019.1589530

Aaronson, L. S., Teel, C. S., Cassmeyer, V., Neuberger, G. B., Pallikkathayil, L., Pierce, J., Press, A. N., Williams, P. D., & Wingate, A. (1999). Defining and measuring fatigue. *Image J Nurs Scholarsh*, *31*(1), 45–50. https://doi.org/10.1111/j.1547-5069.1999.tb00420.x

Ablewhite, J., Condon, L., das Nair, R., Jones, A., Jones, F., Nouri, F., Sprigg, N., Thomas, S., & Drummond, A. (2022). UK clinical approaches to address post-stroke fatigue: Findings from The Nottingham Fatigue after Stroke study. *Int J Ther Rehabil*, *29*(5). https://doi.org/10.12968/ijtr.2021.0163

Ablewhite, J., Nouri, F., Whisker, A., Thomas, S., Jones, F., das Nair, R., Condon, L., Jones, A., Sprigg, N., & Drummond, A. (2022). How do stroke survivors and their caregivers manage post-stroke fatigue? A qualitative study. *Clin Rehabil*. https://doi.org/10.1177/02692155221107738

Ali, A., Morfin, J., Mills, J., Pasipanodya, E. C., Maas, Y. J., Huang, E., Dirlikov, B., Englander, J., & Zedlitz, A. (2022). Fatigue after traumatic brain injury: A systematic review. *J Head Trauma Rehabil*, *37*(4), e249–e257. https://doi.org/10.1097/HTR.0000000000000710

Almhdawi, K. A., Jaber, H. B., Khalil, H. W., Kanaan, S. F., Shyyab, A. A., Mansour, Z. M., & Alazrai, A. H. (2021). Post-stroke fatigue level is significantly associated with mental health component of health-related quality of life: A cross-sectional study. *Qual Life Res*, *30*(4), 1165–1172. https://doi.org/10.1007/s11136-020-02714-z

American Educational Research Association, American Psychological Association, & National Council on Measurement in Education. (2014). *Standards for educational and psychological testing*. American Educational Research Association.

Andersen, G., Christensen, D., Kirkevold, M., & Johnsen, S. P. (2012). Post-stroke fatigue and return to work: A 2-year follow-up. *Acta Neurol Scand*, *125*(4), 248–253. https://doi.org/10.1111/j.1600-0404.2011.01557.x

Bartlett, M. S. (1951). The effect of standardization on a χ^2 approximation in factor analysis. *Biometrika*, *38*(3/4), 337–344. https://doi.org/10.2307/2332580

Bivard, A., Lillicrap, T., Krishnamurthy, V., Holliday, E., Attia, J., Pagram, H., Nilsson, M., Parsons, M., & Levi, C. R. (2017). MIDAS (modafinil in debilitating fatigue after stroke): A randomized, double-blind, placebo-controlled, cross-over trial. *Stroke*, *48*, 1293–1298. https://doi.org/10.1161/STROKEAHA.116.016293

Boehm, N., Muehlberg, H., & Stube, J. E. (2015). Managing poststroke fatigue using telehealth: A case report. *Am J Occup Ther*, *69*(6), Article 6906350020. https://doi.org/10.5014/ajot.2015.016170

Borgaro, S. R., Gierok, S., Caples, H., & Kwasnica, C. (2004). Fatigue after brain injury: Initial reliability study of the BNI Fatigue Scale. *Brain Inj*, *18*(7), 685–690. https://doi.org/10.1080/02699050310001646080

Borsboom, D. (2008). Latent Variable Theory. *Meas Interdiscip Res Perspect*, *6*(1–2), 25–53. https://doi.org/10.1080/15366360802035497

Boter, H., Mänty, M., Hansen, A. M., Hortobágyi, T., & Avlund, K. (2014). Self-reported fatigue and physical function in late mid-life. *J Rehabil Med*, *46*(7), 684–690. https://doi.org/10.2340/16501977-1814

Brioschi, A., Gramigna, S., Werth, E., Staub, F., Ruffieux, C., Bassetti, C., Schluep, M., & Annoni, J.-M. (2009). Effect of modafinil on subjective fatigue in multiple sclerosis and stroke patients. *Eur Neurol*, *62*(4), 243–249. https://doi.org/10.1159/000232927

Brown, T. A. (2015). *Confirmatory factor analysis for applied research* (2. ed). Guilford Press.

Bunzli, S., Maujean, A., Andersen, T. E., & Sterling, M. (2018). Whiplash patients' responses on the Impact of Events Scale-R: Congruent with pain or PTSD symptoms? *Clin J Pain*, *35*(3), 229–237. https://doi.org/10.1097/AJP.0000000000000665

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Res*, *28*, 193–213. https://doi.org/10.1016/0165-1781(89)90047-4

Cantor, J. B., Ashman, T., Bushnik, T., Cai, X., Farrell-Carnahan, L., Gumber, S., Hart, T., Rosenthal, J., & Dijkers, M. P. (2014). Systematic review of interventions for fatigue after traumatic brain injury: A NIDRR traumatic brain injury model systems study. *J Head Trauma Rehabil*, *29*(6), 490–497. https://doi.org/10.1097/HTR.0000000000000102

Cantor, J. B., Ashman, T., Gordon, W., Ginsberg, A., Engmann, C., Egan, M., Spielman, L., Dijkers, M., Flanagan, S., Arvidsson, D., Breeze, J., Cheng, Z., Kramer, A., Morrison, R., Ortiz, A., Schiavetti, S., & Segura, E. (2008). Fatigue after traumatic brain injury and its impact on participation and quality of life. *J Head Trauma Rehabil*, *23*(1), 41–51. https://doi.org/10.1097/01.HTR.0000308720.70288.af

Cappelleri, J. C., Jason Lundy, J., & Hays, R. D. (2014). Overview of classical test theory and item response theory for the quantitative assessment of items in developing patient-reported outcomes measures. *Clin Ther*, *36*(5), 648–662. https://doi.org/10.1016/j.clinthera.2014.04.006

Castillo-Díaz, M., & Padilla, J. L. (2013). How cognitive interviewing can provide validity evidence of the response processes to scale items. *Soc Indic Res*, *114*(3), 963–975. https://doi.org/10.1007/s11205-012-0184-8

Chaudhuri, A., & Behan, P. O. (2004). Fatigue in neurological disorders. *Lancet*, *363*(9413), 978–988. https://doi.org/10.1016/S0140-6736(04)15794-2

Chen, A., Bushmeneva, K., Zagorski, B., Colantonio, A., Parsons, D., & Wodchis, W. P. (2012). Direct cost associated with acquired brain injury in Ontario. *BMC Neurol*, *12*, Article 76. https://doi.org/10.1186/1471-2377-12-76

Chen, F. F. (2007). Sensitivity of goodness of fit indexes to lack of measurement invariance. *Struct Equ Model*, *14*(3), 464–504. https://doi.org/10.1080/10705510701301834

Choi-Kwon, S., Choi, J., Kwon, S. U., Kang, D.-W., & Kim, J. S. (2007). Fluoxetine is not effective in the treatment of post-stroke fatigue: A double-blind, placebo-controlled study. *Cerebrovasc Dis*, *23*(2–3), 103–108. https://doi.org/10.1159/000097045

Christensen, D., Johnsen, S. P., Watt, T., Harder, I., Kirkevold, M., & Andersen, G. (2008). Dimensions of post-stroke fatigue: A two-year follow-up study. *Cerebrovasc Dis*, *26*, 134–141. https://doi.org/10.1159/000139660

Cieza, A., Causey, K., Kamenov, K., Hanson, S. W., Chatterji, S., & Vos, T. (2020). Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: A systematic analysis for the Global Burden of Disease Study 2019. *Lancet*, *396*(10267), 2006–2017. https://doi.org/10.1016/S0140-6736(20)32340-0

Clarke, A., Barker-Collo, S. L., & Feigin, V. L. (2012). Poststroke fatigue: Does group education make a difference? A randomized pilot trial. *Top Stroke Rehabil*, *19*(1), 32–39. https://doi.org/10.1310/tsr1901-32

Connolly, L. J., Rajaratnam, S. M. W., Murray, J. M., Spitz, G., Lockley, S. W., & Ponsford, J. L. (2021). Home-based light therapy for fatigue following acquired brain injury: A pilot randomized controlled trial. *BMC Neurol*, *21*, Article 262. https://doi.org/10.1186/s12883-021-02292-8

Cooper, J., Reynolds, F., & Bateman, A. (2009). An evaluation of a fatigue management intervention for people with acquired brain injury: An exploratory study. *Br J Occup Ther*, *72*(4), 174–179. https://doi.org/10.1177/030802260907200407

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Med Res Methodol*, *11*, Article 100. https://doi.org/10.1186/1471-2288-11-100

Cumming, T. B., & Mead, G. E. (2015). Post-stroke fatigue: Common but poorly understood. In A. Bhalla & J. Birns (Eds.), *Management of Post-Stroke Complications* (pp. 317–345). Springer. https://doi.org/10.1007/978-3-319-17855-4_14

Cumming, T. B., Packer, M., Kramer, S. F., & English, C. (2016). The prevalence of fatigue after stroke: A systematic review and meta-analysis. *Int J Stroke*, *11*(9), 968–977. https://doi.org/10.1177/1747493016669861

de Doncker, W., Dantzer, R., Ormstad, H., & Kuppuswamy, A. (2018). Mechanisms of poststroke fatigue. *J Neurol Neurosurg Psychiatry*, *89*(3), 287–293. https://doi.org/10.1136/jnnp-2017-316007

de Doncker, W., Ondobaka, S., & Kuppuswamy, A. (2021). Effect of transcranial direct current stimulation on post-stroke fatigue. *J Neurol*, *268*, 2831–2842. https://doi.org/10.1007/s00415-021-10442-8 de Groot, M. H., Phillips, S. J., & Eskes, G. A. (2003). Fatigue associated with stroke and other neurologic conditions: Implications for stroke rehabilitation. *Arch Phys Med Rehabil*, *84*(11), 1714–1720. https://doi.org/10.1053/S0003-9993(03)00346-0

DeLuca, J. (2005a). Fatigue, cognition and mental effort. In J. DeLuca (Ed.), *Fatigue as a window to the brain* (pp. 37–57). MIT Press.

DeLuca, J. (2005b). Fatigue: Its definition, its study and its future. In J. DeLuca (Ed.), *Fatigue as a window to the brain* (pp. 319–325). MIT Press.

DeVellis, R. F. (2017). *Scale development: Theory and applications* (4th ed.). SAGE.

Dong, X. L., Sun, X., Sun, W. M., Yuan, Q., Yu, G. H., Shuai, L., & Yuan, Y. F. (2021). A randomized controlled trial to explore the efficacy and safety of transcranial direct current stimulation on patients with post-stroke fatigue. *Medicine*, *100*(41), Article e27504. https://doi.org/10.1097/MD.0000000000027504

Dornonville de la Cour, F. L., Bærentzen, M. B., Forchhammer, B., Tibæk, S., & Norup, A. (2022). Reducing fatigue following acquired brain injury: A feasibility study of high intensity interval training for young adults. *Dev Neurorehabil*, *25*(5), 349–360. https://doi.org/10.1080/17518423.2022.2052374

Dornonville de la Cour, F. L., Norup, A., Andersen, T. E., & Schow, T. (2022). *Defining a treatment model for self-management of fatigue following acquired brain injury: A collective case study using the Rehabilitation Treatment Specification System* [Manuscript submitted for publication]. Department of Psychology, University of Southern Denmark.

Dornonville de la Cour, F. L., Norup, A., Schow, T., & Andersen, T. E. (2021). Evaluation of response processes to the Danish version of the Dutch Multifactor Fatigue Scale in stroke using the Three-Step Test-Interview. *Front Hum Neurosci*, *15*, Article 642680. https://doi.org/10.3389/fnhum.2021.642680

Drummond, A., Nouri, F., Ablewhite, J., Condon, L., das Nair, R., Jones, A., Jones, F., Sprigg, N., & Thomas, S. (2022). Managing post-stroke fatigue: A qualitative study to explore multifaceted clinical perspectives. *Br J Occup Ther*, *85*(7), 505–512. https://doi.org/10.1177/03080226211042269

Duncan, F. H., Greig, C., Lewis, S., Dennis, M., MacLullich, A., Sharpe, M., & Mead, G. E. (2014). Clinically significant fatigue after stroke: A longitudinal cohort study. *J Psychosom Res*, *77*(5), 368–373. https://doi.org/10.1016/j.jpsychores.2014.06.013

Duncan, F. H., Wu, S., & Mead, G. E. (2012). Frequency and natural history of fatigue after stroke: A systematic review of longitudinal studies. *J Psychosom Res*, *73*(1), 18–27. https://doi.org/10.1016/j.jpsychores.2012.04.001

Eilertsen, G., Ormstad, H., & Kirkevold, M. (2013). Experiences of poststroke fatigue: Qualitative meta-synthesis. *J Adv Nurs*, *69*(3), 514–525. https://doi.org/10.1111/jan.12002

Eilertsen, G., Ormstad, H., Kirkevold, M., Mengshoel, A. M., Söderberg, S., & Olsson, M. (2015). Similarities and differences in the experience of fatigue among people living with fibromyalgia, multiple sclerosis, ankylosing spondylitis and stroke. *J Clin Nurs*, *24*(13–14), 2023–2034. https://doi.org/10.1111/jocn.12774

Elbers, R. G., Rietberg, M., Wegen, E., Verhoef, J., Kramer, S., Terwee, C. B., & Kwakkel, G. (2012). Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: A systematic review of measurement properties. *Qual Life Res*, *21*(6), 925–944. https://doi.org/10.1007/s11136-011-0009-2

Evans, R., Scourfield, J., & Murphy, S. (2015). Pragmatic, formative process evaluations of complex interventions and why we need more of them [Editorial]. *J Epidemiol Community Health*, *69*(10), 925–926. https://doi.org/10.1136/jech-2014-204806

Ezekiel, L., Field, L., Collett, J., Dawes, H., & Boulton, M. (2021). Experiences of fatigue in daily life of people with acquired brain injury: A qualitative study. *Disabil Rehabil*, *43*(20), 2866–2874. https://doi.org/10.1080/09638288.2020.1720318

Feigin, V. L., Stark, B. A., Johnson, C. O., Roth, G. A., Bisignano, C., Abady, G. G., Abbasifard, M., Abbasi-Kangevari, M., Abd-Allah, F., Abedi, V., Abualhasan, A., Abu-Rmeileh, N. M., Abushouk, A. I., Adebayo, O. M., Agarwal, G., Agasthi, P., Ahinkorah, B. O., Ahmad, S., Ahmadi, S., … Murray, C. J. L. (2021). Global, regional, and national burden of stroke and its risk factors, 1990–2019: A systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol*, *20*(10), 795–820. https://doi.org/10.1016/S1474-4422(21)00252-0

Franche, R. L., Corbière, M., Lee, H., Breslin, F. C., & Hepburn, C. G. (2007). The Readiness for Return-to-Work (RRTW) scale: Development and validation of a self-report staging scale in lost-time claimants with musculoskeletal disorders. *J Occup Rehabil*, *17*(3), 450–472. https://doi.org/10.1007/s10926-007-9097-9

Green, S. B., & Yang, Y. (2009). Reliability of summed item scores using structural equation modeling: An alternative to coefficient alpha. *Psychometrika*, *74*(1), 155–167. https://doi.org/10.1007/s11336-008-9099-3

Hak, T., & Jansen, H. (2008). The Three-Step Test-Interview (TSTI): An observation-based method for pretesting self-completion questionnaires. *Surv Res Methods*, *2*(3), 143–150. https://doi.org/10.18148/srm/2008.v2i3.1669

Hart, T., Dijkers, M. P., Whyte, J., Turkstra, L. S., Zanca, J. M., Packel, A., van Stan, J. H., Ferraro, M., & Chen, C. (2019). A theory-driven system for the specification of rehabilitation treatments. *Arch Phys Med Rehabil*, *100*(1), 172–180. https://doi.org/10.1016/j.apmr.2018.09.109

Hart, T., Tsaousides, T., Zanca, J. M., Whyte, J., Packel, A., Ferraro, M., & Dijkers, M. P. (2014). Toward a theory-driven classification of rehabilitation treatments. *Arch Phys Med Rehabil*, *95*(1 Suppl 1), S33–S44. https://doi.org/10.1016/j.apmr.2013.05.032

Hart, T., Whyte, J., Dijkers, M., Packel, A., Turkstra, L., Zanca, J., Ferraro, M., Chen, C., & van Stan, J. (2018). *Manual for rehabilitation treatment specification* (Version 6.2). https://acrm.org/acrm-communities/rehabilitation-treatment-specification/manual-for-rehabilitation-treatment-specification/

Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., Bonsel, G., & Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res*, *20*(10), 1727–1736. https://doi.org/10.1007/s11136-011-9903-x

Hjollund, N. H., Andersen, J. H., & Bech, P. (2007). Assessment of fatigue in chronic disease: A bibliographic study of fatigue measurement scales. *Health Qual Life Outcomes*, *5*, Article 12. https://doi.org/10.1186/1477-7525-5-12

Hofer, H., Grosse Holtforth, M., Lüthy, F., Frischknecht, E., Znoj, H., & Müri, R. M. (2014). The potential of a mindfulness-enhanced, integrative neuro-psychotherapy program for treating fatigue following stroke: A preliminary study. *Mindfulness*, *5*(2), 192–199. https://doi.org/10.1007/s12671-012-0167-5

Horn, J. L. (1965). A rationale and test for the number of factors in factor analysis. *Psychometrica*, *30*(2), 179–185. https://doi.org/10.1007/BF02289447

Hulme, K., Safari, R., Thomas, S., Mercer, T., White, C., van der Linden, M., & Moss-Morris, R. (2018). Fatigue interventions in long term, physical health conditions: A scoping review of systematic reviews. *PLoS ONE*, *13*(10), Article e0203367. https://doi.org/10.1371/journal.pone.0203367

Ingles, J. L., Eskes, G. A., & Phillips, S. J. (1999). Fatigue after stroke. *Arch Phys Med Rehabil*, *80*(2), 173–178. https://doi.org/10.1016/S0003-9993(99)90116-8

James, S. L., Bannick, M. S., Montjoy-Venning, W. C., Lucchesi, L. R., Dandona, L., Dandona, R., Hawley, C., Hay, S. I., Jakovljevic, M., Khalil, I., Krohn, K. J., Mokdad, A. H., Naghavi, M., Nichols, E., Reiner, R. C., Smith, M., Feigin, V. L., Vos, T., Murray, C. J. L., … Zaman, S. B. (2019). Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990-2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*, *18*(1), 56–87. https://doi.org/10.1016/S1474-4422(18)30415-0

Jesus, T. S., Papadimitriou, C., Bright, F. A., Kayes, N. M., Pinho, C. S., & Cott, C. A. (2022). Person-centered rehabilitation model: Framing the concept and practice of person-centered adult physical rehabilitation based on a scoping review and thematic analysis of the literature. *Arch Phys Med Rehabil*, *103*, 106–120. https://doi.org/10.1016/j.apmr.2021.05.005

Jha, A., Weintraub, A., Allshouse, A., Morey, C., Cusick, C., Kittelson, J., Harrison-Felix, C., Whiteneck, G., & Gerber, D. (2008). A randomized trial of modafinil for the treatment of fatigue and excessive daytime sleepiness in individuals with chronic traumatic brain injury. *J Head Trauma Rehabil*, *23*(1), 52–63. https://doi.org/10.1097/01.HTR.0000308721.77911.ea

Johansson, B., Bjuhr, H., & Rönnbäck, L. (2012). Mindfulness-based stress reduction (MBSR) improves long-term mental fatigue after stroke or traumatic brain injury. *Brain Inj*, *26*(13–14), 1621–1628. https://doi.org/10.3109/02699052.2012.700082

Johansson, B., Carlsson, A., Carlsson, M. L., Karlsson, M., Nilsson, M. K. L., Nordquist-Brandt, E., & Rönnbäck, L. (2012). Placebo-controlled cross-over study of the monoaminergic stabiliser (−)-OSU6162 in mental fatigue following stroke or traumatic brain injury. *Acta Neuropsychiatr*, *24*(05), 266–274. https://doi.org/10.1111/j.1601-5215.2012.00678.x

Johansson, B., Starmark, A., Berglund, P., Rödholm, M., & Rönnbäck, L. (2010). A self-assessment questionnaire for mental fatigue and related symptoms after neurological disorders and injuries. *Brain Inj*, *24*(1), 2–12. https://doi.org/10.3109/02699050903452961

Johansson, B., Wentzel, A. P., Andréll, P., Odenstedt, J., Mannheimer, C., & Rönnbäck, L. (2014). Evaluation of dosage, safety and effects of methylphenidate on post-traumatic brain injury symptoms with a focus on mental fatigue and pain. *Brain Inj*, *28*(3), 304–310. https://doi.org/10.3109/02699052.2013.865267

Johansson, B., Wentzel, A. P., Andréll, P., Rönnbäck, L., & Mannheimer, C. (2017). Long-term treatment with methylphenidate for fatigue after traumatic brain injury. *Acta Neurol Scand*, *135*(1), 100–107. https://doi.org/10.1111/ane.12587

Johansson, B., Wentzel, A.-P., Andréll, P., Mannheimer, C., & Rönnbäck, L. (2015). Methylphenidate reduces mental fatigue and improves processing speed in persons suffered a traumatic brain injury. *Brain Inj*, *29*(6), 758–765.

Jorgensen, T. D., Pornprasertmanit, S., Schoemann, A. M., & Rosseel, Y. (2021). *semTools: Useful tools for structural equation modeling* (0.5-4) [Computer software]. https://cran.r-project.org/package=semTools

Juengst, S., Skidmore, E., Arenth, P. M., Niyonkuru, C., & Raina, K. D. (2013). Unique contribution of fatigue to disability in community-dwelling adults with traumatic brain injury. *Arch Phys Med Rehabil*, *94*(1), 74–79. https://doi.org/10.1016/j.apmr.2012.07.025

Kaiser, H. F. (1974). An index of factorial simplicity. *Psychometrika*, *39*(1), 31–36. https://doi.org/10.1007/BF02291575

Kaiser, H. F., & Rice, J. (1974). Little Jiffy, Mark IV. *Educ Psychol Meas*, *34*, 111–117. https://doi.org/10.1177/001316447403400115

Kaiser, P. R., Valko, P. O., Werth, E., Thomann, J., Meier, J., Stocker, R., Bassetti, C. L., & Baumann, C. R. (2010). Modafinil ameliorates excessive daytime sleepiness after traumatic brain injury. *Neurology*, *75*(20), 1780–1785. https://doi.org/10.1212/WNL.0b013e3181fd62a2

Karaiskos, D., Tzavellas, E., Spengos, K., Vassilopoulou, S., & Paparrigopoulos, T. (2012). Duloxetine versus citalopram and sertraline in the treatment of poststroke depression, anxiety, and fatigue. *J Neuropsychiatry Clin Neurosci*, *24*(3), 349–353. https://doi.org/10.1176/appi.neuropsych.11110325

Kelley, K. (2020). *MBESS: The MBESS R package* (4.8.0) [Computer software]. https://cran.r-project.org/package=MBESS

Kjeverud, A., Østlie, K., Schanke, A. K., Gay, C., Thoresen, M., & Lerdal, A. (2020). Trajectories of fatigue among stroke patients from the acute phase to 18 months post-injury: A latent class analysis. *PLoS ONE*, *15*(4), Article e0231709. https://doi.org/10.1371/journal.pone.0231709

Kluger, B. M., Krupp, L. B., & Enoka, R. M. (2013). Fatigue and fatigability in neurologic illnesses: Proposal for a unified taxonomy. *Neurology*, *80*(4), 409–416. https://doi.org/10.1212/WNL.0b013e31827f07be

Kolakowsky-Hayner, S. A., Bellon, K., Toda, K., Bushnik, T., Wright, J., Isaac, L., & Englander, J. (2017). A randomised control trial of walking to ameliorate brain injury fatigue: A NIDRR TBI model system centre-based study. *Neuropsychol Rehabil*, *27*(7), 1002–1018. https://doi.org/10.1080/09602011.2016.1229680

Kratz, A. L., Murphy, S. L., Braley, T. J., Basu, N., Kulkarni, S., Russell, J., & Carlozzi, N. E. (2019). Development of a person-centered conceptual model of perceived fatigability. *Qual Life Res*, *28*(5), 1337–1347. https://doi.org/10.1007/s11136-018-2093-z

Krupp, L. B. (2003). *Fatigue* (1st ed). Butterworth-Heinemann.

Krupp, L. B., LaRocca, N. G., Muir-Nash, J., & Steinberg, A. D. (1989). The Fatigue Severity Scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol*, *46*(10), 1121–1123. https://doi.org/10.1001/archneur.1989.00520460115022

Kuppuswamy, A. (2017). The fatigue conundrum. *Brain*, *140*(8), 2240–2245. https://doi.org/10.1093/brain/awx153

Kutlubaev, M. A., Duncan, F. H., & Mead, G. E. (2012). Biological correlates of post-stroke fatigue: A systematic review. *Acta Neurol Scand*, *125*(4), 219–227. https://doi.org/10.1111/j.1600-0404.2011.01618.x

Kyriazos, T. A. (2018). Applied psychometrics: Sample size and sample power considerations in factor analysis (EFA, CFA) and SEM in general. *Psychology*, *9*(8), 2207–2230. https://doi.org/10.4236/psych.2018.98126

Lange, G., Cook, D. B., & Natelson, B. H. (2005). Rehabilitation and treatment of fatigue. In J. DeLuca (Ed.), *Fatigue as a window to the brain* (pp. 301–316). MIT Press.

Launeanu, M. S. (2016). *Response processes as a source of validity evidence in self-report measures: Theoretical and methodological implications* [Doctoral dissertation]. The University of British Columbia. https://doi.org/10.14288/1.0300124

Lenaert, B., Colombi, M., van Heugten, C., Rasquin, S., Kasanova, Z., & Ponds, R. (2019). Exploring the feasibility and usability of the experience sampling method to examine the daily lives of patients with acquired brain injury. *Neuropsychol Rehabil*, *29*(5), 754–766. https://doi.org/10.1080/09602011.2017.1330214

Lenaert, B., van Kampen, N., van Heugten, C., & Ponds, R. (2020). Real-time measurement of post-stroke fatigue in daily life and its relationship with the retrospective Fatigue Severity Scale. *Neuropsychol Rehabil,* Advance online publication. https://doi.org/10.1080/09602011.2020.1854791

Lerdal, A., Bakken, L. N., Kouwenhoven, S. E., Pedersen, G., Kirkevold, M., Finset, A., & Kim, H. S. (2009). Poststroke fatigue—A review. *J Pain Symptom Manage*, *38*(6), 928–949. https://doi.org/10.1016/j.jpainsymman.2009.04.028

Lorentzen, K., Danielsen, M. A., Due Kay, S., & Voss, A. (2014). Validation of the Fatigue Severity Scale in Danish patients with systemic lupus erythematosus. *Dan Med J*, *61*(4), Article A4808. https://ugeskriftet.dk/dmj/validation-fatigue-severity-scale-danish-patients-systemic-lupus-erythematosus

Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Psychology Foundation.

Lynch, J., Mead, G. E., Greig, C., Young, A., Lewis, S., & Sharpe, M. (2007). Fatigue after stroke: The development and evaluation of a case definition. *J Psychosom Res*, *63*(5), 539–544. https://doi.org/10.1016/j.jpsychores.2007.08.004

Ma, H. M., & Zafonte, R. D. (2020). Amantadine and memantine: A comprehensive review for acquired brain injury. *Brain Inj*, *34*(3), 299–315. https://doi.org/10.1080/02699052.2020.1723697

Malley, D., Wheatcroft, J., & Gracey, F. (2014). Fatigue after acquired brain injury: A model to guide clinical management. *Adv Clin Neurosci Rehabil*, *14*(2), 17–19. https://doi.org/10.47795/JVER9544

Markus, K. A., & Borsboom, D. (2013). Philosophical theories of measurement. In *Frontiers of test validity theory: Measurement, causation, and meaning*. Routledge.

McDonald, R. P. (1999). *Test theory: A unified treatment*. Lawrence Erlbaum.

Mead, G. E., Lynch, J., Greig, C., Young, A., Lewis, S., & Sharpe, M. (2007). Evaluation of fatigue scales in stroke patients. *Stroke*, *38*(7), 2090–2095. https://doi.org/10.1161/STROKEAHA.106.478941

Ministry of Higher Education and Science. (2014). *Danish code of conduct for research integrity*. Ministry of Higher Education and Science.

Mollayeva, T., Kendzerska, T., Mollayeva, S., Shapiro, C. M., Colantonio, A., & Cassidy, J. D. (2014). A systematic review of fatigue in patients with traumatic brain injury: The course, predictors and consequences. *Neurosci Biobehav Rev*, *47*, 684–716. https://doi.org/10.1016/j.neubiorev.2014.10.024

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D., & Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ, 350,* Article h1258. https://doi.org/10.1136/bmj.h1258

Multiple Sclerosis Council for Clinical Practice Guidelines. (1998). *Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis*. Paralyzed Veterans of America.

Mundfrom, D. J., Shaw, D. G., & Ke, T. L. (2005). Minimum sample size recommendations for conducting factor analyses. *Int J Test*, *5*(2), 159–168. https://doi.org/10.1207/s15327574ijt0502_4

Naess, H., Nyland, H. I., Thomassen, L., Aarseth, J., & Myhr, K.-M. (2005). Fatigue at long-term follow-up in young adults with cerebral infarction. *Cerebrovasc Dis*, *20*, 245–250. https://doi.org/10.1159/000087706

Naess, H., Waje-Andreassen, U., Thomassen, L., Nyland, H., & Myhr, K.-M. (2006). Health-related quality of life among young adults with ischemic stroke on long-term follow-up. *Stroke*, *37*(5), 1232–1236. https://doi.org/10.1161/01.STR.0000217652.42273.02

National Research Council. (1984). *Cognitive aspects of survey methodology: Building a bridge between disciplines*. National Academy Press. https://doi.org/https://doi.org/10.17226/930

Nguyen, S., McKay, A., Wong, D., Rajaratnam, S. M., Spitz, G., Williams, G., Mansfield, D., & Ponsford, J. L. (2017). Cognitive behavior therapy to treat sleep disturbance and fatigue after traumatic brain injury: A pilot randomized controlled trial. *Arch Phys Med Rehabil*, *98*(8), 1508–1517. https://doi.org/10.1016/j.apmr.2017.02.031

Nguyen, S., Wong, D., McKay, A., Rajaratnam, S. M. W., Spitz, G., Williams, G., Mansfield, D., & Ponsford, J. L. (2019). Cognitive behavioural therapy for post-stroke fatigue and sleep disturbance: A pilot randomised controlled trial with blind assessment. *Neuropsychol Rehabil*, *29*(5), 723–738. https://doi.org/10.1080/09602011.2017.1326945

Norup, A., Kruse, M., Soendergaard, P. L., Rasmussen, K. W., & Biering-Sørensen, F. (2020). Socioeconomic consequences of traumatic brain injury: A Danish nationwide register-based study. *J Neurotrauma*, *37*(24), 2694–2702. https://doi.org/10.1089/neu.2020.7064

Norup, A., Svendsen, S. W., Doser, K., Ryttersgaard, T. O., Frandsen, N., Gade, L., & Forchhammer, H. B. (2019). Prevalence and severity of fatigue in adolescents and young adults with acquired brain injury: A nationwide study. *Neuropsychol Rehabil*, *29*(7), 1113–1128. https://doi.org/10.1080/09602011.2017.1371045

Nunnerley, J., King, M., Hodge, K., Hopkins, P., Stockwell, R., Thorne, N., Snell, D., & Gozdzikowska, K. (2022). Co-design of a therapeutic virtual reality tool to increase awareness and self-management of cognitive fatigue after traumatic brain injury. *Disabil Rehabil Assist Technol*. https://doi.org/10.1080/17483107.2021.2014993

Oervik, M. S., Sejbaek, T., Penner, I. K., Roar, M., & Blaabjerg, M. (2017). Validation of the Fatigue Scale for Motor and Cognitive Functions in a Danish multiple sclerosis cohort. *Mult Scler Relat Disord*, *17*, 130–134. https://doi.org/10.1016/j.msard.2017.07.017

Olesen, J., Gustavsson, A., Svensson, M., Wittchen, H. U., & Jönsson, B. (2012). The economic cost of brain disorders in Europe. *Eur J Neurol*, *19*(1), 155–162. https://doi.org/10.1111/j.1468-1331.2011.03590.x

Padilla, J. L., & Benítez, I. (2014). Validity evidence based on response processes. *Psicothema*, *26*(1), 136–144. https://doi.org/10.7334/psicothema2013.259

Palm, S., Rönnbäck, L., & Johansson, B. (2017). Long-term mental fatigue after traumatic brain injury and impact on employment status. *J Rehabil Med*, *49*(3), 228–233. https://doi.org/10.2340/16501977-2190

Pawson, R., & Tilley, N. (1997). How to construct realistic data: Utilizing stakeholders' knowledge. In *Realistic Evaluation*. Sage.

Penner, I. K., Raselli, C., Stöcklin, M., Opwis, K., Kappos, L., & Calabrese, P. (2009). The Fatigue Scale for Motor and Cognitive Functions (FSMC): Validation of a new instrument to assess multiple sclerosis-related fatigue. *Mult Scler*, *15*(12), 1509–1517. https://doi.org/10.1177/1352458509348519

Pfadenhauer, L. M., Gerhardus, A., Mozygemba, K., Lysdahl, K. B., Booth, A., Hofmann, B., Wahlster, P., Polus, S., Burns, J., Brereton, L., & Rehfuess, E. (2017). Making sense of complexity in context and implementation: The Context and Implementation of Complex Interventions (CICI) framework. *Implement Sci*, *12*, Article 21. https://doi.org/10.1186/s13012-017-0552-5

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *Int J Nurs Stud*, *47*(11), 1451–1458. https://doi.org/10.1016/j.ijnurstu.2010.06.004

Pollock, A., St George, B., Fenton, M., & Firkins, L. (2014). Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers, and health professionals. *Int J Stroke*, *9*(3), 313–320. https://doi.org/10.1111/j.1747-4949.2012.00942.x

Ponsford, J. L., Downing, M. G., Olver, J., Ponsford, M., Acher, R., Carty, M., & Spitz, G. (2014). Longitudinal follow-up of patients with traumatic brain injury: Outcome at two, five, and ten years post-injury. *J Neurotrauma*, *31*(1), 64–77. https://doi.org/10.1089/neu.2013.2997

Ponsford, J. L., Schönberger, M., & Rajaratnam, S. M. W. (2015). A model of fatigue following traumatic brain injury. *J Head Trauma Rehabil*, *30*(4), 277–282. https://doi.org/10.1097/HTR.0000000000000049

Poulsen, M. B., Damgaard, B., Zerahn, B., Overgaard, K., & Rasmussen, R. S. (2015). Modafinil may alleviate poststroke fatigue: A randomized, placebo-controlled, double-blinded trial. *Stroke*, *46*(12), 3470–3477. https://doi.org/10.1161/STROKEAHA.115.010860

Poulsen, M. B., Skovbølling, S. L., Kruuse, C., Overgaard, K., & Rasmussen, R. S. (2020). How to identify fatigue in stroke patients: An investigation of the post-stroke fatigue case definition validity. *Top Stroke Rehabil*, *27*(5), 369–376. https://doi.org/10.1080/10749357.2019.1704387

QSR International Pty Ltd. (2020). *NVivo* (1.6.1) [Computer software]. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

R Core Team. (2022). *R: A language and environment for statistical computing* (4.2.0) [Computer software]. R Foundation for Statistical Computing. https://www.r-project.org/

Rabin, R., & de Charro, F. (2001). EQ-5D: A measure of health status from the EuroQol Group. *Ann Med*, *33*(5), 337–343. https://doi.org/10.3109/07853890109002087

Raina, K. D., Morse, J. Q., Chisholm, D., Whyte, E. M., & Terhorst, L. (2022). An internet-based self-management intervention to reduce fatigue among people with traumatic brain injury: A pilot randomized controlled trial. *Am J Occup Ther*, *76*(4), 7604205100. https://doi.org/10.5014/ajot.2022.048587

Revelle, W. (2020). *psych: Procedures for personality and psychological research* (2.1.3) [Computer software]. Northwestern University. https://cran.r-project.org/package=psych Version = 2.1.3

Riley, E. A. (2017). Patient fatigue during aphasia treatment: A survey of speech-language pathologists. *Commun Disord Q*, *38*(3), 143–153. https://doi.org/10.1177/1525740116656330

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In A. M. Huberman & M. B. Miles (Eds.), *The qualitative researcher's companion* (pp. 305–329). SAGE Publications, Inc. https://doi.org/10.4135/9781412986274.n12

Rosseel, Y. (2012). lavaan: An R package for structural equation modeling. *J Stat Softw*, *48*(2), 1–36. https://doi.org/10.18637/jss.v048.i02

Rudberg, A. S., Berge, E., Laska, A. C., Jutterström, S., Näsman, P., Sunnerhagen, K. S., & Lundström, E. (2021). Stroke survivors' priorities for research related to life after stroke. *Top Stroke Rehabil*, *28*(2), 153–158. https://doi.org/10.1080/10749357.2020.1789829

Schönberger, M., Reutens, D., Beare, R., O'Sullivan, R., Rajaratnam, S. M. W., & Ponsford, J. L. (2017). Brain lesion correlates of fatigue in individuals with traumatic brain injury. *Neuropsychol Rehabil*, *27*(7), 1056–1070. https://doi.org/10.1080/09602011.2016.1154875

Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. C. Wright, & M. Johnston (Eds.), *Causal and control beliefs* (pp. 35–37). NFER-Nelson.

Sechrest, L., Fay, T. L., & Hafeez Zaidi, S. M. (1972). Problems of translation in cross-cultural research. *J Cross Cult Psychol*, *3*(1), 41–56. https://doi.org/10.1177/002202217200300103

Sheng, P., Hou, L., Wang, X., Wang, X., Huang, C., Yu, M., Han, X., & Dong, Y. (2013). Efficacy of modafinil on fatigue and excessive daytime sleepiness associated with neurological disorders: A systematic review and meta-analysis. *PLoS ONE*, *8*(12), Article e81802. https://doi.org/10.1371/journal.pone.0081802

Sibbritt, D., Bayes, J., Peng, W., Maguire, J., & Adams, J. (2022). Associations between fatigue and disability, depression, health-related hardiness and quality of life in people with stroke. *J Stroke Cerebrovasc Dis*, *31*(7), Article 106543. https://doi.org/10.1016/j.jstrokecerebrovasdis.2022.106543

Sinclair, K. L., Ponsford, J. L., Taffe, J., Lockley, S. W., & Rajaratnam, S. M. W. (2014). Randomized controlled trial of light therapy for fatigue following traumatic brain injury. *Neurorehabil Neural Repair*, *28*(4), 303–313. https://doi.org/10.1177/1545968313508472

Skogestad, I. J., Kirkevold, M., Indredavik, B., Gay, C. L., & Lerdal, A. (2019). Lack of content overlap and essential dimensions: A review of measures used for post-stroke fatigue. *J Psychosom Res*, *124*, Article 109759. https://doi.org/10.1016/j.jpsychores.2019.109759

Smets, E. M. A. A., Garssen, B., Bonke, B., & de Haes, J. C. J. M. J. M. (1995). The Multidimensional Fatigue Inventory (MFI) psychometric qualities of an instrument to assess fatigue. *J Psychosom Res*, *39*(3), 315–325. https://doi.org/10.1016/0022-3999(94)00125-o

Srisurapanont, K., Samakarn, Y., Kamklong, B., Siratrairat, P., Bumiputra, A., Jaikwang, M., & Srisurapanont, M. (2021). Blue-wavelength light therapy for posttraumatic brain injury sleepiness, sleep disturbance, depression, and fatigue: A systematic review and network meta-analysis. *PLoS ONE*, *16*(2), Article e0246172. https://doi.org/10.1371/journal.pone.0246172

Staub, F., & Bogousslavsky, J. (2001a). Post-stroke depression or fatigue? [Editorial]. *Eur Neurol*, *45*(1), 3–5. https://doi.org/10.1159/000052081

Staub, F., & Bogousslavsky, J. (2001b). Fatigue after stroke: A major but neglected issue. *Cerebrovasc Dis*, *12*(2), 75–81. https://doi.org/10.1159/000047685

Stubberud, J., Edvardsen, E., Schanke, A.-K., Lerdal, A., Kjeverud, A., Schillinger, A., & Løvstad, M. (2019). Description of a multifaceted intervention programme for fatigue after acquired brain injury: A pilot study. *Neuropsychol Rehabil*, *29*(6), 946–968. https://doi.org/10.1080/09602011.2017.1344132

Sundhedsdatastyrelsen. (2020). *Dataopgørelser vedrørende voksne med erhvervet hjerneskade [Data statements concerning adults with acquired brain injury]*. https://sundhedsdatastyrelsen.dk/-/media/sds/filer/find-tal-og-analyser/sygdomme-og-behandlinger/erhvervet-hjerneskade/dataopgoerelser-vedroerende-voksne-med-erhvervet-hjerneskade.pdf

Sundhedsstyrelsen. (2011). *Hjerneskaderehabilitering – en medicinsk teknologivurdering [Brain injury rehabilitation – a health technology assessment]*. https://www.sst.dk/da/udgivelser/2011//-/media/Udgivelser/2011/Publ2011/MTV/Hjerneskaderehabilitering/Hjerneskaderehabilitering-%E2%80%93-en-medicinsk-teknologivurdering-Hovedrapport.ashx

Svetina, D., Rutkowski, L., & Rutkowski, D. (2020). Multiple-group invariance with categorical outcomes using updated guidelines: An illustration using Mplus and the lavaan/semTools packages. *Struct Equ Model*, *27*(1), 111–130. https://doi.org/10.1080/10705511.2019.1602776

Tang, W. K., Lu, J. Y., Chen, Y. K., Mok, V. C., Ungvari, G. S., & Wong, K. S. (2010). Is fatigue associated with short-term health-related quality of life in stroke? *Arch Phys Med Rehabil*, *91*(10), 1511–1515. https://doi.org/10.1016/j.apmr.2010.06.026

Teng, C. H., Phonyiam, R., Davis, L. L., & Anderson, R. A. (2022). Adaptation to poststroke fatigue in stroke survivors and their care partners: A scoping review. *Disabil Rehabil*. https://doi.org/10.1080/09638288.2022.2084775

Terwee, C. B., Prinsen, C. A. C., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: A Delphi study. *Qual Life Res*, *27*(5), 1159–1170. https://doi.org/10.1007/s11136-018-1829-0

Thomas, K., Hjalmarsson, C., Mullis, R., & Mant, J. (2019). Conceptualising post-stroke fatigue: A cross-sectional survey of UK-based physiotherapists and occupational therapists. *BMJ Open*, *9*, Article e033066. https://doi.org/10.1136/bmjopen-2019-033066

Tremayne, J. E., Freeman, J., & Coppola, A. (2021). Stroke survivors' experiences and perceptions of post-stroke fatigue education in the subacute phase of stroke: The FASE qualitative study. *Br J Occup Ther*, *84*(2), 111–121. https://doi.org/10.1177/0308022620963741

Tyson, S. F., & Brown, P. (2014). How to measure fatigue in neurological conditions? A systematic review of psychometric properties and clinical utility of measures used so far. *Clin Rehabil*, *28*(8), 804–816. https://doi.org/10.1177/0269215514521043

Ulrichsen, K. M., Kaufmann, T., Dørum, E. S., Kolskår, K. K., Richard, G., Alnæs, D., Arneberg, T. J., Westlye, L. T., & Nordvik, J. E. (2016). Clinical utility of mindfulness training in the treatment of fatigue after stroke, traumatic brain injury and multiple sclerosis: A systematic literature review and meta-analysis. *Front Psychol*, *7*, Article 912. https://doi.org/10.3389/fpsyg.2016.00912

Ulrichsen, K. M., Kolskår, K. K., Richard, G., Pedersen, M. L., Alnaes, D., Dørum, E. S., Sanders, A.-M., Tornås, S., Maglanoc, L. A., Engvig, A., Ihle-Hansen, H., Nordvik, J. E., & Westlye, L. T. (2021). No effect of tDCS on fatigue and depression in chronic stroke patients: An exploratory randomized sham-controlled trial combining tDCS with computerized cognitive training. *MedRxiv*. https://doi.org/10.1101/2021.06.22.21258133

van de Port, I. G. L., Kwakkel, G., Schepers, V. P. M., Heinemans, C. T. I., & Lindeman, E. (2007). Is fatigue an independent factor associated with activities of daily living, instrumental activities of daily living and health-related quality of life in chronic stroke? *Cerebrovasc Dis*, *23*, 40–45. https://doi.org/10.1159/000095757

van Heest, K. N. L., Mogush, A. R., & Mathiowetz, V. G. (2017). Effects of a one-to-one fatigue management course for people with chronic conditions and fatigue. *Am J Occup Ther*, *71*(4), Article 7104100020. https://doi.org/10.5014/ajot.2017.023440

van Stan, J. H., Dijkers, M. P., Whyte, J., Hart, T., Turkstra, L. S., Zanca, J. M., & Chen, C. (2019). The Rehabilitation Treatment Specification System: Implications for improvements in research design, reporting, replication, and synthesis. *Arch Phys Med Rehabil*, *100*(1), 146–155. https://doi.org/10.1016/j.apmr.2018.09.112

Visser-Keizer, A. C., Hogenkamp, A., Westerhof-Evers, H. J., Egberink, I. J. L., & Spikman, J. M. (2015). Dutch Multifactor Fatigue Scale: A new scale to measure the different aspects of fatigue after acquired brain injury. *Arch Phys Med Rehabil*, *96*(6), 1056–1063. https://doi.org/10.1016/j.apmr.2014.12.010

Watt, T., Groenvold, M., Bjorner, J. B., Noerholm, V., Rasmussen, N.-A., & Bech, P. (2000). Fatigue in the Danish general population. Influence of sociodemographic factors and disease. *J Epidemiol Community Health*, *54*(11), 827–833. http://www.jstor.org/stable/25569305

Whitehead, L. C. (2009). The measurement of fatigue in chronic illness: A systematic review of unidimensional and multidimensional fatigue measures. *J Pain Symptom Manage*, *37*(1), 107–128. https://doi.org/10.1016/j.jpainsymman.2007.08.019

Whitehead, L. C., Unahi, K., Burrell, B., & Crowe, M. T. (2016). The experience of fatigue across long-term conditions: A qualitative meta-synthesis. *J Pain Symptom Manage*, *52*(1), 131–143. https://doi.org/10.1016/j.jpainsymman.2016.02.013

Whyte, J. (2014). Contributions of treatment theory and enablement theory to rehabilitation research and practice. *Arch Phys Med Rehabil*, *95*(1 Suppl 1), S17–S23. https://doi.org/10.1016/j.apmr.2013.02.029

Whyte, J., Dijkers, M. P., Hart, T., van Stan, J. H., Packel, A., Turkstra, L. S., Zanca, J. M., Chen, C., & Ferraro, M. (2019). The importance of voluntary behavior in rehabilitation treatment and outcomes. *Arch Phys Med Rehabil*, *100*(1), 156–163. https://doi.org/10.1016/j.apmr.2018.09.111

Wickham, H. (2016). *ggplot2: Elegant graphics for data analysis*. Springer.

Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. SAGE.

Wilson, L., Wilson, L., Stewart, W., Dams-O'connor, K., Diaz-Arrastia, R., Horton, L., Menon, D. K., & Polinder, S. (2017). The chronic and evolving neurological consequences of traumatic brain injury. *Lancet Neurol*, *16*, 813–825. https://doi.org/10.1016/S1474-4422(17)30279-X

Wong, G., Westhorp, G., Greenhalgh, J., Manzano, A., Jagosh, J., & Greenhalgh, T. (2017). Quality and reporting standards, resources, training materials and information for realist evaluation: The RAMESES II project. *Health Serv Deliv Res*, *5*(28). https://doi.org/10.3310/hsdr05280

World Health Organization. (2021, November 10). *Rehabilitation*. https://www.who.int/news-room/fact-sheets/detail/rehabilitation

World Medical Association. (2013). World Medical Association declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA*, *310*(20), 2191–2194. https://doi.org/10.1001/jama.2013.281053

Wu, S., Chalder, T., Anderson, K. E., Gillespie, D., Macleod, M. R., & Mead, G. E. (2017). Development of a psychological intervention for fatigue after stroke. *PLoS ONE*, *12*(8), Article e0183286. https://doi.org/10.1371/journal.pone.0183286

Wu, S., Kutlubaev, M. A., Chun, H.-Y. Y., Cowey, E., Pollock, A., Macleod, M. R., Dennis, M., Keane, E., Sharpe, M., & Mead, G. E. (2015). Interventions for post-stroke fatigue. *Cochrane Database Syst Rev*. https://doi.org/10.1002/14651858.CD007030.pub3

Wu, S., Mead, G. E., Macleod, M., & Chalder, T. (2015). Model of understanding fatigue after stroke. *Stroke*, *46*(3), 893–898. https://doi.org/10.1161/STROKEAHA.114.006647

Xu, G.-Z., Li, Y.-F., Wang, M.-D., & Cao, D.-Y. (2017). Complementary and alternative interventions for fatigue management after traumatic brain injury: A systematic review. *Ther Adv Neurol Disord*, *10*(5), 229–239. https://doi.org/10.1177/1756285616682675

Ymer, L., McKay, A., Wong, D., Frencham, K., Grima, N., Tran, J., Nguyen, S., Junge, M., Murray, J., Spitz, G., & Ponsford, J. (2021). Cognitive behavioural therapy versus health education for sleep disturbance and fatigue after acquired brain injury: A pilot randomised trial. *Ann Phys Rehabil Med*, *64*, Article 101560. https://doi.org/10.1016/j.rehab.2021.101560

Zanca, J. M., Turkstra, L. S., Chen, C., Packel, A., Ferraro, M., Hart, T., van Stan, J. H., Whyte, J., & Dijkers, M. P. (2019). Advancing rehabilitation practice through improved specification of interventions. *Arch Phys Med Rehabil*, *100*(1), 164–171. https://doi.org/10.1016/j.apmr.2018.09.110

Zedlitz, A. M. E. E., Rietveld, T. C. M., Geurts, A. C., & Fasotti, L. (2012). Cognitive and graded activity training can alleviate persistent fatigue after stroke: A randomized, controlled trial. *Stroke*, *43*(4), 1046–1051. https://doi.org/10.1161/STROKEAHA.111.632117

8 Appendices

Appendix A:	Paper I
Appendix B:	Paper II
Appendix C:	Paper III
Appendix D:	Dutch Multifactor Fatigue Scale–Danish
Appendix E:	Interview Guide for the Case Study on Energy Management
Appendix F:	Interview Guide for Cognitive Interviewing on Dutch Multifactor Fatigue Scale–Danish
Appendix G:	The Initial Model on Energy Management

Appendix A

Paper I

Dornonville de la Cour, F. L., Norup, A., Andersen, T. E., Schow, T. (2022) *Defining a treatment model for self-management of fatigue following acquired brain injury: A collective case study using the Rehabilitation Treatment Specification System* [Manuscript submitted for publication]. Department of Psychology, University of Southern Denmark.

The paper is not included in the publicly available electronic version of this thesis.

Appendix B

Paper II

Dornonville de la Cour, F. L., Norup, A., Schow, T. & Andersen, T. E. (2021) Evaluation of response processes to the Danish version of the Dutch Multifactor Fatigue Scale in stroke using the Three-Step Test-Interview. *Front Hum Neurosci*, 15, Article 642680. https://doi.org/10.3389/fnhum.2021.642680

Paper II was published in *Frontiers of Human Neuroscience* on 6 May 2021. The paper is not included in the publicly available electronic version of this thesis but can be accessed at https://doi.org/10.3389/fnhum.2021.642680.

Appendix C

Paper III

Dornonville de la Cour, F. L., Schow, T., Andersen, T. E., Petersen, A. H., Zornhagen, G., Visser-Keizer, A. C., Norup, A. (2022) *Measurement properties of the Dutch Multifactor Fatigue Scale in early and late rehabilitation of acquired brain injury in Denmark* [Manuscript submitted for publication]. Department of Psychology, University of Southern Denmark.

The paper is not included in the publicly available electronic version of this thesis.

Appendix D

Dutch Multifactor Fatigue Scale–Danish

The original Danish translation of the Dutch Multifactor Fatigue Scale is not included in the publicly available electronic version of this thesis.

Based on findings in this thesis, it is suggested to rephrase Item 24 to reduce syntactic complexity: From "*Jeg har ikke brug for at hvile mig for at komme igennem dagen*" to "*Jeg kan komme igennem dagen uden behov for at hvile mig*". Regarding Item 29, the term "complaints" needs clarification, and it is proposed to rephrase "*Træthed er min værste klage*" to "*Træthed er mit største problem*". Whether these revisions mitigate any problems need to be evaluated in future research. In the interim, the revisions are recommended, as they are supported by substantial evidence on the nature of the problems.

Appendix E

Interview Guide for the Case Study on Energy Management

Two versions of the interview guide were developed: one for service users, and one for service providers. They are both provided (in Danish) on the following pages. The questionnaire was used to facilitate the interview; ratings on the items were not analyzed.

Interviewguide

Instruktion:

Tak for at du vil deltage i dette interview. Formålet med interviewet er at blive klogere på, hvordan vores forløb hjælper folk med at håndtere træthed i hverdagen. Vi har på forhånd gjort os nogle tanker om, hvordan vi tror at forløbet kan hjælpe folk. Men eftersom du har oplevet forløbet på egen krop, har du en særlig viden, som vi gerne vil lære af. Vi vil derfor gerne høre om dine erfaringer og perspektiv på vores tanker omkring forløbet.

Interviewet har tre trin. I første trin vil jeg stille dig nogle åbne spørgsmål om dine oplevelser af forløbet. I næste trin vil jeg give dig et spørgeskema, som handler om hvordan vi tror forløbet hjælper folk. Jeg skal bede dig om at besvare spørgeskemaet ud fra dine egne oplevelser, og jeg vil gerne have at du tænker højt, mens du besvarer spørgeskemaet. Det vil sige, at du skal læse spørgsmålene højt og sige alt hvad du tænker på, mens du svarer på spørgsmålene. I det sidste trin vil jeg spørge ind til dine svar på spørgeskemaet. Har du nogen spørgsmål inden vi går i gang? Er du klar? Godt, så går vi i gang.

Trin 1: Åbne spørgsmål

1. Hvordan har din oplevelse af forløbet været?
2. Har du oplevet et udbytte af forløbet?
    a. Hvis ja: Hvad tænker du har ændret sig? Kom gerne med eksempler
    b. Hvis nej:
        i. Hvad ville du ønske, at forløbet kunne have hjulpet dig med?
        ii. Kunne noget have været gjort anderledes?
        iii. [Gå videre til spørgsmål 4]
3. Vi er meget interesserede i hvad det er ved forløbet, der er virkningsfuldt. Hvorfor tror du, at forløbet har hjulpet?
    a. Stil gerne uddybende spørgsmål til hvordan specifikke aktiviteter/indsigter har hjulpet (referér evt. til specifikke ændringer beskrevet af informanten), fx:
        i. Hvad gav det her forløb som var nyt for dig?
        ii. Hvad var det ved X, der har hjulpet dig?
        iii. Tror du at det primært har at gøre med nye strategier og redskaber eller nye måder at tænke på?
        iv. Så hvordan var det egentlig at forløbet hjalp dig?
4. Der er mange ideer om, hvordan forløbet kan hjælpe folk, og vi tror at det kan være meget forskelligt fra person til person.
    a. Hvad tænker du har været væsentligt for at du kunne opnå et udbytte af forløbet?
    b. Hvad tænker du kan være hæmmende for at opnå et udbytte af forløbet?
5. Hvis du kunne ændre noget ved forløbet for at gøre det bedre, hvad ville du så ændre og hvorfor?
6. Hvad tænker du ellers vi skal vide for virkelig at forstå, hvordan forløbet har virket for dig?

Trin 2: Spørgeskema (næste side)

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Her er 25 udsagn, som handler om forskellige måder, hvorpå rehabiliteringsforløbet kan hjælpe folk. Du bedes venligst tage stilling til hvert udsagn ud fra, hvordan du har oplevet dit rehabiliteringsforløb.

Du svarer ved at sætte ét kryds ud for hvert udsagn alt efter hvordan du synes det passer på dig.

		Slet ikke	En smule	Nogenlunde	I høj grad
1	Forløbet har gjort mig klogere på min træthed	☐	☐	☐	☐
2	Forløbet har gjort mig mere opmærksom på, hvordan jeg kan undgå at blive for træt i hverdagen	☐	☐	☐	☐
3	Forløbet har gjort mig klogere på hvad der skal til for at jeg kan arbejde på trods af træthed	☐	☐	☐	☐
4	Forløbet har givet mig redskaber til at håndtere træthed i min hverdag	☐	☐	☐	☐
5	Forløbet har hjulpet mig med at finde gode måder at restituere på	☐	☐	☐	☐
6	Forløbet har medvirket til, at jeg har ændret mine forventninger til mig selv	☐	☐	☐	☐
7	Forløbet har gjort mig mere opmærksom på, hvad der er vigtigt for mig at bruge min energi på	☐	☐	☐	☐
8	Forløbet har betydet at jeg møder mere forståelse for min træthedsproblematik	☐	☐	☐	☐
9	Forløbet har betydet at jeg er mere fysisk aktiv i min hverdag	☐	☐	☐	☐
10	Forløbet har hjulpet mig med at få en bedre nattesøvn	☐	☐	☐	☐
11	Forløbet har givet mig en bedre forståelse for, hvad der gør mig træt	☐	☐	☐	☐
12	Forløbet har hjulpet mig med at tage bedre hensyn til min træthed i planlægning af aftaler og aktiviteter	☐	☐	☐	☐
13	Forløbet har hjulpet mig tilbage i arbejde under forhold, hvor der tages hensyn til min træthed	☐	☐	☐	☐
14	Forløbet har hjulpet mig med at klare opgaver på måder, så de passer bedre til mit energiniveau	☐	☐	☐	☐
15	Forløbet har givet mig strategier, som kan hjælpe mig, når jeg er ved at blive for træt	☐	☐	☐	☐

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16	Forløbet har hjulpet mig med at lægge bedre mærke til tegn på mental træthed	☐	☐	☐	☐
17	Forløbet har gjort mig bedre til at bruge hvil og pauser til at passe på min energi	☐	☐	☐	☐
18	Forløbet har hjulpet mig med at sætte mere realistiske mål for mig selv	☐	☐	☐	☐
19	Forløbet har hjulpet mig med at bruge min energi på de ting, som er vigtige for mig	☐	☐	☐	☐
20	Forløbet har hjulpet mig med at fortælle andre i min omgangskreds om min træthed	☐	☐	☐	☐
21	Forløbet har hjulpet mig med at finde ud af, hvordan jeg kan være fysisk aktiv i hverdagen	☐	☐	☐	☐
22	Forløbet har hjulpet mig med at få en mere stabil døgnrytme	☐	☐	☐	☐
23	Forløbet har givet mig en bedre forståelse for, hvad der giver mig energi	☐	☐	☐	☐
24	Forløbet har givet mig en bedre forståelse for, hvordan sanseindtryk påvirker mit energiniveau	☐	☐	☐	☐
25	Forløbet har givet min arbejdsgiver og/eller nærmeste kolleger bedre mulighed for at imødekomme mine behov i forhold til min træthed	☐	☐	☐	☐

Udviklet af Frederik Lehman Dornonville de la Cour, neuropsykolog

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Interviewguide

Instruktion:

Tak for at du vil deltage i dette interview. Formålet med interviewet er at blive klogere på, hvordan vores rehabiliteringsforløb hjælper folk med at håndtere træthed i hverdagen. Du har været involveret i et konkret rehabiliteringsforløb, som vi har studeret systematisk, og du har i den forbindelse gjort dig nogle erfaringer med rehabiliteringsindsatsen. Vi vil derfor gerne lære af dine erfaringer med dette forløb for at blive klogere på indsatsen.

Jeg vil gerne stille dig nogle spørgsmål om dine oplevelser af forløbet. Har du nogen spørgsmål inden vi går i gang? Er du klar? Godt, så går vi i gang.

1. Hvordan har din oplevelse af forløbet været som helhed?
    a. Hvordan var forløbet i overordnede træk?

2. Kan du fortælle mig hvad din rolle i forløbet har været?

3. Hvad oplever du at borgeren fik ud af forløbet?
    a. Kan du komme med et eksempel? / Kan du uddybe?
    b. Prompt, hvis det ikke nævnes:
        i. Fik borgeren mere energi som følge af forløbet?
        ii. Fik borgeren en mere struktureret hverdag?
    c. Er der nogle ting, du ville ønske borgeren havde fået med, som ikke lykkedes?

4. Tror du at alle får det samme ud af forløbet, som [navn] gjorde? På hvilke måder kan det have været forskelligt?

5. Vi er meget interesserede i hvad det er ved forløbet, der virker. På hvilke måder tror du at forløbet har hjulpet eller gjort en forskel for borgeren?
    a. Spørg gerne ind til hvordan forløbet har tilvejebragt til de konkrete ændringer, der er blevet nævnt ovenfor ved pkt. 3
    b. UDDYB hvordan de specifikke aktiviteter har hjulpet, fx:
        i. Hvad var det ved [aktiviteten], som var nyt for borgeren?
        ii. Hvad var det ved [aktiviteten], der har hjulpet personen?
        iii. På hvilken måde hjalp [aktiviteten] med at borgeren fik et udbytte af forløbet?
    c. Tror du at forløbet har ændret på den måde borgeren håndterer sin træthed? På hvilken måde? Kan du komme med nogle eksempler?
        i. Fx måden borgeren forstår træthed?

6. Der er mange ideer om, hvordan forløbet kan hjælpe folk, og vi tror at det kan være meget forskelligt fra person til person.
    a. Hvad tænker du har været væsentligt for at netop denne person kunne få et optimalt udbytte af forløbet?
    b. Hvad tænker du kan have været hæmmende for at personen kunne få et optimalt udbytte af forløbet?

7. Energiforvaltning virker formentlig forskelligt fra sted til sted. Hvad tænker du er vigtigt for effekten ved den måde vi laver energiforvaltning her på BOMI / Cervello?

8. Hvis du kunne ændre noget ved forløbet for at det blev bedre, hvad ville du så ændre og hvorfor?

9. Hvad tænker du ellers vi skal vide for virkelig at forstå, hvordan forløbet har virket for denne borger?

Udviklet af Frederik L. Dornonville de la Cour
på baggrund af RAMESES II Project materiale

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Appendix F

Interview Guide for Cognitive Interviewing on Dutch Multifactor Fatigue Scale–Danish

The interview guide that was developed for cognitive interviewing in Paper II is provided (in Danish) on the following pages.

INTERVIEW GUIDE TIL COGNITIVE INTERVIEWING AF DMFS

Intro

Før vi går i gang med interviewet, vil jeg gerne forklare dig om, hvordan interviewet kommer til at foregå. Jeg vil gerne bede dig om, at besvare dette spørgeskema som måler symptomer på træthed. Formålet med din deltagelse i dette projekt er, at vi gerne vil finde ud af hvordan du forstår spørgsmålene. Du vil derfor opleve, at jeg vil bede dig om at uddybe dine tanker om besvarelsen. Der er ikke nogen rigtige eller forkerte svar. I første trin af interviewet vil jeg bede dig om, at læse spørgsmålene op for derefter at besvare spørgsmålet samtidig med at du "tænker højt" - dvs. fortæl mig alt du tænker, mens du læser og svarer på spørgsmålene. Undervejs vil jeg sidde ved siden af og tage noter. Jeg vil kun bryde ind for at minde dig om at tænke højt, hvis du kommer til at glemme det. Andet trin i interviewet vil bestå af, at jeg stiller dig nogle spørgsmål om de tanker, som du sagde højt. Tredje trin vil bestå af, at jeg stiller dig nogle mere specifikke spørgsmål ind til hvordan du tolker spørgsmålene. Hvis du får brug for det, kan vi tage en pause på 5-10 minutter undervejs. Hvis du er klar, så starter vi med første trin.

Trin 1 (observation)

På denne side vil du finde 38 udsagn. Ved at du vurderer hvert af disse udsagn, vil vi få et indtryk af hvordan du har haft det den sidste måned. Du svarer ved at sætte et kryds i en af kasserne fra 1 til 5 alt efter hvor enig eller uenig du er med udsagnet. 1 er "Nej, jeg er helt uenig", 2 er "Jeg er overvejende uenig", 3 er "Neutral", 4 er "Jeg er overvejende enig", og 5 er "Ja, jeg er helt enig" (peg på kasserne imens). Jeg vil bede dig om at læse spørgsmålene op og tænke højt mens du svarer på hver af dem.

Trin 2 (follow-up)

Spørg ind til de ting, du har bemærket og noteret undervejs i trin 1. (Notér evt. på spørgeskemaet)

Trin 3

Specifikke spørgsmål til de 38 items til trin 3 i TSTI:

1. *"Jeg er ofte træt" [Indvirkning af træthed]*
   Kan du forklare hvorfor du har svaret X? // I hvilke situationer oplever du at være træt? // Hvor ofte oplever du at være træt?
2. *"Jeg planlægger bevidst, hvornår jeg hviler" [Coping med træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvilke måder "hviler" du på? // Hvad gør du for at planlægge dine hvil?
3. *"Jeg kan følge med i samtaler uden at blive træt" [Mental træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvordan mærker du, at du bliver træt?
4. *"Jeg bliver træt om eftermiddagen" [Tegn og konsekvenser af træthed]*
   Kan du forklare hvorfor du har svaret X? // Kan du beskrive hvordan du oplever træthed i løbet af en hel dag?
5. *"Jeg føler mig i god fysisk form" [Fysisk træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved begrebet "fysisk form"?
6. *"Trætheden forhindrer min evne til at gøre de ting jeg vil" [Indvirkning af træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvilke specifikke ting tænkte du på, da du skulle besvare dette spørgsmål?
7. *"Ting som rører mig følelsesmæssigt, gør mig træt" [Tegn og konsekvenser]*
   Kan du forklare hvorfor du har svaret X? // Hvilke specifikke ting tænkte du på, da du skulle besvare dette spørgsmål?
8. *"Jeg udtrætter altid mig selv" [Coping med træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved begrebet "udtrætter"? // Hvilke situationer tænkte du på, da du skulle besvare dette spørgsmål?
9. *"Jeg har et godt fysisk helbred" [Fysisk træthed]*
   Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved begrebet "fysisk helbred"?
10. *"At tænke gør mig træt" [Mental træthed]*
    Kan du forklare hvorfor du har svaret X? // I hvilke situationer har du oplevet at det at tænke gjorde dig træt?
11. *"Selv når jeg er meget træt, kommer jeg mig hurtigt" [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved ordet "hurtigt" - kan du give et konkret eksempel på en situation, hvor du har været meget træt?

12. *"Jeg gør tingene færdige, også selvom jeg er træt" [Coping med træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare dette spørgsmål? // Hvad er årsagen til at du gjorde tingene færdige?
13. *"Jeg kan blive overvældet af træthed" [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // I hvilke situationer har du oplevet at blive overvældet af træthed? // Hvad betyder det for din hverdag, at du kan blive overvældet af træthed?
14. *"Jeg vågner udhvilet efter en god nats søvn" [Fysisk træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvordan føles det, når du er "udhvilet"?
15. *Andre mennesker lægger mærke til, at jeg er træt, før jeg selv gør [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // Hvordan oplever du, at andre mennesker lægger mærke til, at du er træt?
16. *Jeg undgår at blive overtræt [Coping med træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved begrebet "overtræt"? // Hvad gør du for at undgå at blive overtræt?
17. *Megen stimulation, såsom aktiviteter eller støj, gør mig træt [Mental træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare spørgsmålet?
18. *Fysisk anstrengelse gør mig træt [Fysisk træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare spørgsmålet?
19. *Når jeg er træt, får jeg hovedpine [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // Hvad er årsagen til, at du får hovedpine?
20. *Jeg er træt hver dag [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad betyder det for din hverdag, at du er træt?
21. *Når jeg er træt, reagerer jeg mere følelsesladet [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // I hvilke situationer har du reageret mere følelsesladet? // Hvad er årsagen til at du reagerer mere følelsesladet?
22. *Jeg kommer let over min træthed [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved begrebet "at komme let over…"? // I hvilke situationer har du kommet dig let over din træthed?

23. *Når jeg er træt, har jeg svært ved at slippe mine tanker [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, at du har svært ved at slippe dine tanker?
24. *Jeg har ikke brug for at hvile mig for at komme igennem dagen [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved udtrykket ”at komme igennem dagen”, da du skulle besvare dette spørgsmål? // Hvad gør at du har brug for at hvile dig?
25. *Min krop gør ondt, når jeg er træt [Fysisk træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, når din krop gør ondt? // Hvad er årsagen til, at din krop gør ondt?
26. *Jeg lider af svær træthed [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad betyder det for dig at ”lide af svær træthed”?
27. *Jeg har svært ved at koncentrere mig, når jeg er træt [Mental træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, når du har svært ved at koncentrere dig?
28. *Når jeg er træt, siger jeg ting, jeg fortryder bagefter [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare dette spørgsmål? // Hvad er årsagen til, at du siger ting, som du fortryder bagefter?
29. *Træthed er min vigtigste klage [Indvirkning af træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved udtrykket ”min vigtigste klage”?
30. *Jeg har kun lidt energi [Fysisk træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, når du kun har lidt energi?
31. *Efter at have brugt mit hoved en masse, kan jeg stadig være træt dagen efter [Tegn og konsekvenser]*
    Kan du forklare hvorfor du har svaret X? // I hvilke situationer bruger du dit hoved en masse? // Hvordan viser trætheden sig dagen efter?
32. *Jeg laver fejl, når jeg er træt [Mental træthed]*
    Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare dette spørgsmål? // I disse situationer - hvad er årsagen til, at du laver fejl?

33. *Træthed påvirker hele mit liv [Indvirkning af træthed]*
Kan du forklare hvorfor du har svaret X? // Hvad forstod du ved udtrykket ”hele mit liv” i spørgsmålet?
34. *Mine vanskeligheder bliver værre, når jeg er træt [Mental træthed]*
Kan du forklare hvorfor du har svaret X? // Hvilke ”vanskeligheder” tænkte du på, da du skulle besvare dette spørgsmål? // Hvad er årsagen til at vanskelighederne bliver værre?
35. *Når jeg er for træt, kan jeg pludselig ikke mere [Indvirkning af træthed]*
Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, når du ikke kan mere? // Kan du komme med et konkret eksempel?
36. *Jeg lader ofte mig selv blive overtræt, når omstændighederne kræver det [Coping med træthed]*
Kan du forklare hvorfor du har svaret X? // Hvilke situationer tænkte du på, da du skulle besvare dette spørgsmål? Hvad er årsagen til, at du lader dig selv blive overtræt?
37. *Når jeg er for træt, kan jeg pludselig ikke tænke mere [Mental træthed]*
Kan du forklare hvorfor du har svaret X? // Hvordan viser det sig, når du ikke kan tænke mere? // Kan du komme med et konkret eksempel?
38. *Jeg lider frygtelig pga. min træthed [Indvirkning af træthed]*
Kan du forklare hvorfor du har svaret X? // På hvilke måder gør din træthed, at du lider frygteligt?

Appendix G

The Initial Model on Energy Management

The initial model on EM that was developed in co-production workshops is not included in the publicly available electronic version of this thesis.