

Malin Rangø Andersen

# Cognitive Impairment after Acquired Brain Injury: Experiences with Daily Life Activities and Occupational Therapy Assessment and Intervention

Master's thesis in Physical Activity and Health - Occupational  
Science

Supervisor: Linda Stigen

May 2023



Malin Rangø Andersen

**Cognitive Impairment after Acquired  
Brain Injury:  
Experiences with Daily Life Activities  
and Occupational Therapy Assessment  
and Intervention**

Master's thesis in Physical Activity and Health - Occupational Science  
Supervisor: Linda Stigen  
May 2023

Norwegian University of Science and Technology  
Faculty of Medicine and Health Sciences  
Department of Neuromedicine and Movement Science



Norwegian University of  
Science and Technology



## Infographic

# Cognitive Impairment after Acquired Brain Injury

## Experiences with Daily Life Activities and Occupational Therapy Assessment and Intervention

→ Informants: Two women and two men experiencing cognitive impairment after acquired brain injury. Aged 63-97 years old.

→ Reduced memory and attention  
Communication and language deficits  
Vision impairment  
Fatigue



*"We were in a training kitchen. And I was supposed to do it all by myself. It was so difficult. I have been working as a kitchen manager for many years. It was no fun at all"*



*"I notice that when I have visitors during the weekend and such, I get some extra energy"*

### Experiences

#### Daily Life Activities

- Performance affected by cognitive impairment
- Maintaining roles, habits and routines
- Focusing on meaningful activities
- Performing activities in their local environment
- Support from family and friend

#### Occupational Therapy Assessment and Intervention

- Being observed during performance of activities
- Performing tasks targeting specific cognitive functions
- Practicing activities
- Adapting activities
- Resuming daily life activities

## **Abstract**

**Background:** In the coming years countries will experience a demographic shift towards an older population. Acquired brain injuries (ABI) such as stroke and traumatic brain injury (TBI) is expected to increase. Research indicates that 24-96% of people with ABI experience cognitive impairment. Cognitive impairment can lead to challenges with thinking, feeling and/or acting and the ability to maintain or acquire skills. There is identified a lack of studies on cognition, mood and participation, as well as effective occupational therapy assessment and intervention. The research aim for this project were: How does people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention?

**Method:** Four semi-structured interviews were conducted with participants from two different municipalities in Norway who is experiencing cognitive impairment after ABI and is receiving occupational therapy in their municipality. The data was analysed and coded with an interpretative phenomenological approach.

**Results:** The participants experienced sudden and unexpected changes in life when sustaining an ABI. Following the ABI, they experienced various cognitive impairments that affected performance of daily life activities. Resources such as internal motivation, family and friends, and being able to return to their home positively influenced their ability to manage their situation. In addition, occupational therapy intervention and assessment were important in order to manage their cognitive impairments and resume activities. Lastly, experiencing meaningfulness through performance of activities alone and together with others provided a sense of mastery and happiness.

**Conclusion:** The results from this study highlight the importance of increasing knowledge of cognitive impairment, utilizing formal and informal resources and providing occupational therapy assessment and intervention that focus on meaningful activities in order to enable activity and participation for people experiencing cognitive impairment after ABI.

**Key words:** Acquired brain injury, cognitive impairment, activity, participation, occupational therapy.

## **Sammendrag**

**Bakgrunn:** I de kommende årene vil verden oppleve et demografisk skifte mot en eldre befolkning. Det er forventet en økning tilfeller av ervervede hjerneskader som hjerneslag og traumatisk hjerneskade. Forskning indikerer at 24-96% av mennesker med ervervet hjerneskade får kognitiv svikt. Kognitiv svikt kan føre til utfordringer med tenking, emosjoner og/eller handling, samt evnen til å vedlikeholde eller lære nye ferdigheter. Det er oppdaget mangel på forskning angående kognisjon, emosjonelle forhold og deltakelse i etterkant av ervervet hjerneskade. Videre er det behov for forskning på effektive ergoterapeutiske metoder for kartlegging og intervensjon. Forskningsspørsmålet for dette prosjektet var: Hvordan opplever mennesker med ervervet hjerneskade kognitive svikt i daglige aktiviteter og deltakelse i ergoterapeutisk kartlegging og intervensjon?

**Metode:** Fire semi-strukturerte intervjuer ble gjennomført med deltakere fra to ulike kommuner i Norge som opplever kognitiv svikt etter ervervet hjerneskade og mottar ergoterapi fra kommunen. Datamateriale ble analysert med fortolkende fenomenologisk metode.

**Resultat:** Deltakerne i studien opplevde plutselig og uventet endring i sitt liv når de fikk en ervervet hjerneskade. I etterkant opplevde de svikt i ulike kognitive funksjoner som påvirket utførelse av deres daglige aktiviteter. Resurser som indre motivasjon, familie og venner, og å ha muligheten til å bo i eget hjem bidro til å økt håndterbarhet. I tillegg var deltakelse i ergoterapeutisk kartlegging og intervensjon viktig for å lære å håndtere deres kognitive svikt og gjenoppta aktiviteter. Å oppleve meningsfullhet gjennom hverdagsaktivitet, både alene og med andre, førte til opplevelse av mestring og glede.

**Konklusjon:** Resultatene fra denne studien fremhever viktigheten av økt kunnskap om kognitiv svikt, å benytte tilgjengelige ressurser og å tilby ergoterapeutisk kartlegging og intervensjon som fokuserer på meningsfull aktivitet. Dette bidro til å muliggjøre aktivitet og deltakelse for personer med kognitiv svikt etter ervervet hjerneskade.

**Nøkkelord:** Ervervet hjerneskade, kognitiv svikt, aktivitet, deltakelse, ergoterapi.

## **Acknowledgements**

An interesting, engaging and educational project have come to an end. To all the participants who contributed to this project by sharing your personal experiences with me, thank you for your time and devotion to this important research. This would not be possible without you. I would also like to express my gratitude to Dr. Linda Stigen for sharing your impressive knowledge on this subject and guiding me through the project. I have really enjoyed collaborating with you. And to my family, words cannot describe how grateful I am for your endless love and support. You mean the world to me.



# Table of Content

<b>1.0 INTRODUCTION</b> .....	<b>1</b>
1.1 COGNITIVE IMPAIRMENT AND DAILY LIFE ACTIVITIES.....	3
1.2 COGNITIVE IMPAIRMENT AND OCCUPATIONAL THERAPY.....	4
1.3 RESEARCH STATEMENT .....	5
<b>2.0 THEORETICAL BACKGROUND</b> .....	<b>7</b>
2.1 DOING, BEING, BELONGING AND BECOMING.....	7
2.2 THE SALUTOGENIC MODEL OF HEALTH .....	8
2.2.1 <i>Sense of Coherence</i> .....	8
2.2.2 <i>Generalized Resistance Resources</i> .....	9
2.3 APPLICATION OF THEORETICAL BACKGROUND .....	9
<b>3.0 METHODS</b> .....	<b>11</b>
3.1 RECRUITMENT PROCESS AND PARTICIPANTS .....	11
3.2 DATA COLLECTION.....	12
3.3 DATA ANALYSIS.....	13
3.4 ETHICAL CONSIDERATIONS .....	15
<b>4.0 RESULTS</b> .....	<b>16</b>
4.1 SUDDEN CHANGES IN HEALTH AND FUNCTION .....	16
4.2 IMPAIRMENT OF COGNITIVE FUNCTIONS AND DAILY LIFE ACTIVITIES.....	17
4.3 SUPPORT FROM FAMILY AND FRIENDS.....	18
4.4 EXPERIENCES WITH RECEIVING OCCUPATIONAL THERAPY .....	19
4.5 THE IMPORTANCE OF MASTERING DAILY LIFE.....	21
<b>5.0 DISCUSSION</b> .....	<b>23</b>
5.1 COMPREHENSIBILITY: COMING TO TERMS WITH UNEXPECTED CHANGES .....	23
5.2 MANAGEABILITY: LEARNING TO MANAGE DAILY LIFE ACTIVITIES WITH COGNITIVE IMPAIRMENT.....	25
5.3 MEANINGFULNESS: EXPERIENCING MEANINGFULNESS IN NEW WAYS OF DOING ACTIVITIES .....	28
<b>6.0 CONCLUSION</b> .....	<b>31</b>
<b>7.0 STRENGTHS AND LIMITATIONS</b> .....	<b>32</b>
<b>8.0 IMPLICATIONS FOR FUTURE RESEARCH</b> .....	<b>33</b>
<b>REFERENCES</b> .....	<b>34</b>

## 1.0 Introduction

Norway, and countries across the world are experiencing increased longevity and a demographic shift in their population (FHI, 2022; WHO, 2022). People live longer and countries throughout the world is anticipating a significant increase in their older population (FHI, 2022; UN, 2019; WHO 2022). The ageing population is seen as a human success story (UN, 2019). It reflects medical advancements, successful public health measures and economic and social development tackling injuries and diseases that have affected human longevity in the past (UN, 2019). People aged 60 and over belongs to the fastest growing age group (WHO, 2002), and in year 2030 one in six people are expected to be 60 years and older (WHO, 2022).

A natural part of aging is the gradual changes in physical and mental capacities (WHO, 2022). As people age, the risk of frailty, chronic diseases and impaired functioning increases (FHI, 2022). Further, decline in cognitive functions such as memory, reasoning, processing speed and executive functions can occur from early adulthood (Deary et al., 2009). In addition to normal cognitive changes related to age, diseases and trauma can cause cognitive impairment (Murman, 2015). Degenerative ageing processes are a significant cause of non-communicable diseases (NCDs) (Jin et al., 2015) and according to World Health Organization (WHO) (2002) NCDs are the leading cause of mortality, morbidity and disability for individuals in all regions of the world.

Among NCDs, acquired brain injuries (ABI) such as stroke and traumatic brain injuries (TBI) are expected to have an increasing impact on public health (Hyder et al., 2007; Helse- og omsorgsdepartementet, 2017). ABI can result in significant cognitive, behavioral, emotional and physical changes depending on the cause, and which part of the brain that is affected (Helsenorge, 2020). Cognitive impairment is often described as “invisible” impairment and are associated with functional problems that can be challenging to understand and difficult to manage (Kristensen & Birkmose, 2013; Maskill & Tempest, 2017). Furthermore, cognitive impairment is a frequent sequel to ABI, and research indicates that 24-96% of people with ABI experience impairment in one or several cognitive domains such as attention, memory and executive functions (Chiavaroli et al., 2016; Douiri, 2013; Gutiérrez Pérez et al., 2011; Jokinen et al., 2015; Rasquin et al., 2004). The prevalence of cognitive impairment found in

studies differs because of variations in sample characteristics, definitions of impairment, assessment methods, country and race (Jokinen et al., 2015; Sun et al., 2014).

Cognitive impairments can affect the ability to acquire or maintain skills, and cause challenges with thinking, feeling and or/acting (Maskill & Tempest, 2017). Additionally, disabilities can lead to challenges meeting immediate and long-term needs, as well as maintaining desired roles (Atchinson & Dirette, 2007). Also, milder cognitive deficits can affect peoples' performance of activities, independent functioning and quality of life (Jokinen et al., 2015). Notably, cognitive impairment has also been reported by people considered being in good clinical recovery with no or minor physical disability (Jokinen et al., 2015; Kapoor et al., 2017). However, previous studies have identified a lack of studies regarding cognition, participation and mood as sequels after ABI (Jokinen et al., 2015; Kapoor et al., 2017).

The anticipated increase in older adults will lead to an escalating need for health care services (Helse- og omsorgsdepartementet, 2017). As a result of the implementation of the Norwegian Coordination Reform in 2009, greater responsibility is placed on health care services in the municipality (Ness & Horghagen, 2020). It is emphasized that people should perform their daily life activities in their local environment (Ness & Horghagen, 2020). Occupational therapists (OTs) aim to find solutions when there is a gap between health and the requirements of daily life (Norsk Ergoterapeutforbund, 2017). OTs are dedicated to enable activity and participation, as well as an inclusive environment for all, regardless of illness or functional level (Norsk Ergoterapeutforbund, 2017).

In Norway most OTs work in municipal health care services such as habilitation, rehabilitation and palliative care (Ness & Horghagen, 2020), and can therefore become an important profession in order to meet the anticipated challenges within healthcare services and enabling people to live in their homes for as long as possible. Among OTs working in municipalities, research regarding interventions and collaboration with patients experiencing cognitive impairment is highly prioritized (Gramstad & Nilsen, 2017). In recent studies (Holmqvist, Kamwendo & Ivarsson., 2009; Stigen, Bjørk & Lund, 2019) OTs have expressed doubt regarding whether they have enough knowledge about intervention methods for people with cognitive impairment and it has been pointed out a need for development of effective assessments and interventions for this patient group in municipal health care services.

## **1.1 Cognitive Impairment and Daily Life Activities**

Cognitive impairment following ABI causes disability in complex ways that affects several aspects of daily life (Kapoor et al., 2017). A variety of cognitive, emotional and behavioral changes have been reported in studies on recovery after ABI (Erikson et al., 2007; Erikson, Karlsson & Tham, 2016; Kapoor et al., 2017; Pappadis et al., 2019). For instance, reduced memory and thinking abilities, changes in language and communication, visual-spatial processing, depression and anxiety (Erikson et al., 2007; Erikson, Karlsson & Tham, 2016; Kapoor et al., 2017; Pappadis et al., 2019). Initially after injury, longing for their previous life, self-esteem, competencies and activities could act as a motivational factor, but also feel like an unattainable goal (Erikson et al., 2007; Erikson, Karlsson & Tham, 2016). Further, after acquiring an ABI, social relations are described as an important factor contributing to a sense of security and belonging, as well as progress and continuity (Erikson, Karlsson & Tham, 2016). However, experiences with isolation, social loss and friction such as break-ups, losing contact with close friends and feeling ignored by ones' personal network have also been reported (Erikson, Karlsson & Tham, 2016; Pappadis et al., 2019).

As a consequence of cognitive impairment, performance of daily life activities can change from routine and automated performance, to difficulties mastering new and former activities (Erikson et al., 2007). Decreased thinking abilities and memory can cause challenges with logical thinking and having to reflect on each step in an activity to achieve a coherent performance (Erikson et al., 2007; Pappadis et al., 2019). As well as keeping focus and being attentive during activities, impairment in thinking abilities and memory can cause challenges with problem solving, remembering appointments and forgetting what to say in a conversation (Erikson, Karlsson & Tham, 2016; Pappadis et al., 2019). However, being able to choose if, when, where and how activities are performed is described as essential, regardless of whether the person needs support or not during performance (Häggström & Larsson Lund, 2008). Additionally, being able to perform activities according to personal preferences and satisfaction is found to be important in order to facilitate engagement. Further, changing or giving up preferences and habits are challenging. Loss of or difficulties adapting meaningful activities to enable performance is considered a negative influence on engagement (Häggström & Larsson Lund, 2008). However, when activities can't be performed as usual, participation is positively influenced by developing new preferences and new ways to perform them satisfactorily (Häggström & Larsson Lund, 2008).

Even 11-13 years after being diagnosed with an ABI, research have found that people still struggled with cognitive impairment to an extent that negatively affected their daily life activities (Eriksson, Karlsson & Tham, 2016). People with ABI have described continued challenges with finding their new identity, a feeling of alienation from their body and fatigue which restricts performance of activities and social participation. Further, people with ABI have expressed frustration and inadequacy with not being able to rely on their cognitive abilities when performing activities (Eriksson, Karlsson & Tham, 2016).

## **1.2 Cognitive Impairment and Occupational Therapy**

OTs core competency is to enable activity and participation for everyone, regardless of diagnosis and functional level (Norsk Ergoterapeutforbund, 2017). Moreover, OTs have in-depth knowledge of how activity is linked to and affects identity and health (Norsk Ergoterapeutforbund, 2017). Further, OTs have an essential role in assisting persons with cognitive impairment create or maintain meaningful lives in their environment (AOTA, 1999). Activities are utilized to improve cognitive, communicative and sensorimotor skills (Norsk Ergoterapeutforbund, 2017). OTs focus on how cognition relates to performance of activities and participation (Obermeyer et al., 2019). Further, they assess cognition from various perspectives (Obermeyer et al., 2019) and implements effective interventions to address impairments in a wide range of cognitive domains aiming to increase participation in activities (AOTA, 1999). By assessing the association between the persons' identity, activities and context, and how they influence each other makes OTs capable to address cognitive impairments that negatively influence persons daily life (Obermeyer et al., 2019).

In previous research, OTs have revealed that the patients' cognitive impairment often was difficult and time consuming to detect (Holmqvist, Kamwendo & Ivarsson, 2009). When assessing patients with cognitive impairment OTs have reported use of standardized and non-standardized methods, or a combination to ensure reliable and valid results (Holmqvist, Kamwendo & Ivarsson, 2009; Stigen, Bjørk & Lund, 2019). The most frequently used assessment methods reported by OTs were conversations, observations and standardized assessments (Holmqvist, Kamwendo & Ivarsson, 2009). Among OTs working in municipal health care services, conducting observations in activities such as kitchen activities, morning routines, getting dressed and shopping is preferred when assessing the impact of cognitive impairment (Stigen, Bjørk & Lund, 2023). When required, the OTs also conducted

standardized tests such as MMSE, Clock Drawing test and Trailmaking A+B. However, the OTs highlighted that these desk-top assessments did not necessary reflect the patients' performance of activities, which was their main concern in most cases (Stigen, Bjørk & Lund, 2023). The standardized assessment was usually conducted upon request by doctors or when assessing if the patient required different living arrangements. However, being thorough during the assessment period was important in order to identify the issue and target the intervention to the patients' needs (Stigen, Bjørk & Lund, 2023).

Within rehabilitation there is two main approaches to cognitive impairment, the adaptive approach and the remedial approach (Katz & Hadas, 1995). The adaptive approach aims to restore cognitive functions and the remedial approach aims to compensate for impairments in activities (Holmqvist, Kamwendo & Ivarsson, 2009). Interventions can therefore target the persons skills, adapting the activity or make changes in the environment to enhance or maintain function and independence (AOTA, 1999). Occupational therapy interventions focus on engagement in activities meaningful to the person (Obermeyer et al., 2019). This was also highlighted by OTs working in municipal services who emphasized focusing on activities that were meaningful to their client by asking the question "What is meaningful for you?" (Stigen, Bjørk & Lund, 2019). Research show that the most frequent intervention provided by Norwegian OTs mainly focused on environmental modification and implementation of assistive devices to enhance performance of activities and enable the clients to live in their own home (Stigen, Bjørk & Lund, 2022). Additionally, the OTs would provide interventions concentrating on daily life activities and cognitive training, which was also the most preferred interventions among the OTs (Stigen, Bjørk & Lund, 2022).

### **1.3 Research Statement**

The aging population is considered a great economic and social challenge that countries worldwide will face the next years (UN, 2017; UN, 2019). Additionally, cognitive impairment and ABI are expected to increase with the demographic shift (Hyder et al., 2007; Helse- og omsorgsdepartementet, 2017). As described, cognition is a significant factor influencing peoples' ability to master daily life activities (Erikson et al., 2007; Erikson, Karlsson & Tham, 2016; Pappadis et al., 2019). Cognition also affects how we communicate with others and how we integrate the world around us (Murman, 2015). The current assessment methods of functional outcome after ABI focus mainly on physical disability, on the other hand, attention towards mood, cognition and return to activities and social participation is insufficient

(Jokinen et al., 2015; Kapoor et al., 2017; Pappadis et al., 2019). Moreover, increased research on cognitive impairment has been highly requested by OTs in Norway (Gramstad & Nilsen, 2017).

Within innovation, research and improvement of health services persons with brain injury and brain diseases need to be considered key contributors to creating and developing health care services (Helse- og omsorgsdepartementet, 2017). Combining patients and healthcare professional's knowledge and experiences increases the chances of utilizing new knowledge and ensures that healthcare services meets the target group to a larger extent. Which could make the healthcare services better for both the patient and the healthcare professionals (Helse- og omsorgsdepartementet, 2017). Research on occupational therapy assessment and interventions is necessary to ensure meaningful development and changes for this client group (Erikson et al., 2007), and in order to achieve successful implementation it is essential to listen to the recipients. Research on this subject will be an important contribution to meet government and policy makers aim to promote healthy ageing, as well as preventing and treating NCDs and chronic conditions (UN, 2017). Based on this, increased research and knowledge about cognitive impairments after ABI are necessary and critical in order to enable activity and participation for the aging population, as well as ensuring effective occupational therapy assessment and intervention. The research aim for this project were:

*How does people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention?*

## **2.0 Theoretical Background**

Within occupational science and occupational therapy, it is believed that people have an intrinsic need for activities and that performing activities is vital for peoples' health and well-being (Wilcock, 1993; Jarman, 2010; Christiansen & Townsend, 2010). Engaging in activities allows people to acquire skills, connect with others and the community, and discover meaning in life (Law, 2002). Activity is also thought to be central to how people create and maintain their identity (Christiansen, 1999). In order to gain a deeper understanding of how people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention, Doing, being, belonging and becoming and The Salutogenic Model of Health has been chosen to provide insight into the study's aim. Due to the scope of this study they will not be described in their entirety, only selected parts seen relevant is presented in the following chapter. Further, their application to the study is described.

### **2.1 Doing, Being, Belonging and Becoming**

Doing, being, belonging and becoming is a framework that aims to capture the complexity of activity and how different dimensions of activities influence who we are and what we do (Wilcock & Hocking, 2015). Doing refers to the activities we perform and participate in. Doing includes all types of activities, for example physical, mental, social, self-chosen or obligatory activity. Being describes ones' roles and interests. Being reflects a persons' sense of self and who they are because of the activities they are doing (Wilcock & Hocking, 2015). Through doing activities, affiliation is created to other people, communities or places allowing an experience of feeling connected to others and being in the right place. Belonging is associated with a sense of meaning, acceptance, happiness and security in relationships and communities (Wilcock & Hocking, 2015). Through doing, being and belonging people change and develop from day to day, and over time. This could be explained as becoming more mature, more knowledgeable or becoming different. Through activities alone or with others, performance results in various forms of becoming, both on an individual level or social, communal or global level (Wilcock & Hocking, 2015)



## **2.2 The Salutogenic Model of Health**

The Salutogenic Model of Health describes how people can experience good physical and mental health despite hardships encountered throughout a lifespan (Antonovsky, 2012). The Salutogenic Model of Health, hereby referred to as salutogenesis, is regarded as a counterpart to pathogenesis and traditional medical perspectives. Salutogenesis (2012) proposes a perspective of health and disease as a continuum and explain that at any point in life, all humans are somewhere on the health-disease continuum. Health is viewed as a subjective and dynamic variable. Further, salutogenesis seeks to understand where an individual is on the continuum and which factors possibly promotes movement towards the health-end of the continuum. The main focus is directed towards the origins of health and how health occurs, rather than risk factors and disease (Antonovsky, 2012).

### **2.2.1 Sense of Coherence**

A central component within Salutogenesis is the sense of coherence (SOC), which is thought to represent a person's perspective of life and ability to manage stressful situations (Antonovsky, 2012). Further, SOC is essential for a person to maintain its position on the health-disease continuum and hopefully move towards the health-end of the continuum (Antonovsky, 2012). SOC consists of and is measured by three core components: comprehensibility, manageability and meaningfulness (Antonovsky, 2012). The first component, comprehensibility, refers to the degree a person experiences internal and external stimulus as understandable and as structured, clear and cohesive information, rather than chaotic, unexpected and incomprehensible (Antonovsky, 2012). The second component, manageability, refers to which extent a person perceives to have sufficient formal or informal resources available to handle the demands proposed by the stimuli one encounters (Antonovsky, 2012). A strong sense of manageability increases the possibility that one is able to handle the unexpected and unwanted experiences in life and is less likely to consider oneself a victim of the circumstances or thinking life is unfair (Antonovsky, 2012). The last component, meaningfulness, describes the feeling of whether life is emotionally comprehensible and meaningful, and that challenges and demands encountered through life is worth committing to and engaging in to find a solution or work through (Antonovsky, 2012). Two individuals living rather similar lives or sharing an experience can cope in quite different ways, which is dependent on their SOC (Antonovsky, 1996). If a person with a strong SOC meets a stressor they will most likely: be motivated or wish to cope (meaningfulness),

understand the challenge (comprehensibility) and believe they have the resources to cope (manageability) (Antonovsky, 1996).

### **2.2.2 Generalized Resistance Resources**

Generalized Resistance Resources (GRR) is defined as factors that enable effective protection or response towards stressors and challenging situations encountered through life (Antonovsky, 2012). Stressors are defined as demands there is no immediate or automatic adaptive response to. However, the effect of the stressor is that it creates a state of tension. GRR are thought to create life experiences characterized by internal coherence, co-determination and a balance between under- and overload. In this way, GRR creates or strengthens a strong SOC (Antonovsky, 2012). When confronted with a stressor, a person with a strong SOC will reflect on previous experiences and apply the most appropriate resistance resource they have at their disposal (Antonovsky, 1996; Antonovsky, 2012). Prior to mobilizing resources, to be able to manage the situation, the person needs to understand the consequences and scope of the situation (Antonovsky, 2012). A person with a strong SOC is able to structure information in order to find a solution. It is challenging to predict whether a stressful life event or situation have negative impact on a persons' SOC (Antonovsky, 2012). It is the level of SOC of the person experiencing the stressor that determines whether the outcome will be harmful, neutral or beneficial (Antonovsky, 2012).

Examples of GRR (Bhattacharya et al., 2020):

- Physical and chemical: housing, money, food, health and absence of disease, clothing etc.
- Cognitive: education, intelligence, knowledge
- Emotional: self-esteem
- Interpersonal relations: social support
- Macrosocial: religion and culture

### **2.3 Application of Theoretical Background**

Salutogenesis will be used to explore the participants perspective of life after experiencing ABI and cognitive impairment, as well as their ability to manage the unexpected changes in their health and daily life. Moreover, whether there is a component of SOC or GRR that enables or inhibits return to daily life activities after disease and disability.

Doing, being, belonging and becoming will be utilized to analyse how sudden disease and disability affects various dimensions of the participants daily life activities. In addition, the researcher will examine whether the participants level of SOC has an impact on doing, being, belonging and becoming. Salutogenesis and doing, being, belonging and becoming will be applied when discussing the projects results and previous research with the aim of gaining a deeper understanding of the participants experiences and which factors influence activity and participation with cognitive impairment after ABI.

### **3.0 Methods**

In order to explore the subject of this master project and collect suitable data, a qualitative research design was chosen. Interpretative phenomenological analysis (IPA) is a qualitative research approach that aims to describe how people comprehend major life experiences (Smith, Flowers & Larkin, 2012). IPA attempts to describe perspective, meaning and the significance of an experience through peoples embodied experiences (Smith, Flowers & Larkin, 2012). Therefore, IPA was chosen in order to examine how people with ABI experience cognitive impairment in daily life activities and participating in occupational therapy assessment and intervention. In the following chapter data collection and analysis are described.

#### **3.1 Recruitment Process and Participants**

The recruitment of participants for this study was conducted in collaboration with an ongoing PhD project. The PhD project investigates the effectiveness of the Perceive Recall Plan and Perform (PRPP) in community-based rehabilitation (Lindstad et al., 2021). The target group is persons 65 years and older experiencing challenges with performing daily life activities due to cognitive challenges after ABI (Lindstad et al., 2021). Trained occupational therapists in two community-based rehabilitation units provides nine individual sessions of PRPP for participants in the project (Lindstad et al., 2021).

Participants in the PhD project were assessed for participation in this study. In order to be included, the participants were required to experience cognitive impairment following an ABI and participating in occupational therapy assessment and intervention in their municipality. Communication difficulties such as impulsive and expressive aphasia or dysarthria were assessed for inclusion by the degree of their difficulties. Participants with mild to moderate aphasia were included, whereas participants with severe aphasia were excluded. Participants were excluded if they were diagnosed with congenital brain damage, dementia diagnosis or developmental disability. Additionally, participants with severe hearing loss or language barriers affecting the patients' ability to understand instructions were excluded. Further, participants with severe arousal problems and physical disabilities that constrained performance of several daily activities were excluded.

The participants who met the inclusion criteria received an information letter about the master project and was asked to participate by their OT. Contact information to participants who

wished to partake in the project was provided for the researcher, via the project manager. The researcher further contacted the participant to confirm their participation and arrange the time, date and place for the interview. During the recruitment process, the researcher had challenges with including a sufficient number of participants. This was due to several participants being excluded by the project criteria's and participants declining participation. Therefore, an application to change the recruitment method was sent to and approved by the Regional Ethical Committee (REK). The permission made it possible for the OTs who referred participants to this project, to search through patient archives and recruit previous patients with cognitive impairment after ABI and who had received occupational therapy in their municipality.

A total of eleven people was assessed for participation in this project during the recruitment period. Three were excluded due to the inclusion criteria, three was not asked due to complications regarding their situation and one declined participation. Four people from two different municipalities in Norway agreed to participate and were included in the study. Two were recruited from the PhD project and two were recruited by their OT. Additionally, participant one and two were accompanied by their spouse during the interview. All participants had cognitive impairment due to ABI and received occupational therapy in their municipality. Participant characteristics are presented in table 1.

Table 1: Participant characteristics

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>ABI cause</b>
P1	Male	87	Stroke
P2	Male	63	Traumatic brain injury
P3	Female	77	Stroke
P4	Female	80	Stroke

### **3.2 Data Collection**

Based on the project aim, interviews were considered the most suitable method to collect relevant data. The purpose of interviews is to understand the participants daily life described from their own perspective (Kvale & Brinkmann, 2015). The interview structure is similar to everyday conversation, but as a professional interview it involves a certain method and

technique (Kvale & Brinkmann, 2015). A semi-structured interview guide consisting of 10 questions were prepared in advance of the interviews. The questions were phrased openly to encourage the participants to share their experience in depth (Smith, Flowers & Larkin, 2012). The researcher actively listened to the participants story and asked follow-up question about the participants thoughts and experiences consecutively (Smith, Flowers & Larkin, 2012).

In advance of the interview, the researcher informed the participant about the project and repeated key elements from the information letter. The right to withdraw consent at any point where emphasized to all participants before starting the interview. Two interviews were conducted in the participants home, one was conducted over FaceTime and one were conducted on a telephone call. The reason why all interviews weren't conducted in person was limited time and travel opportunities for both the researcher and the participants. All interviews were carried out in the participants native language, Norwegian. The interviews lasted between 30-60 minutes and were taped with a digital recorder. All interviews were transcribed verbatim by the researcher.

### **3.3 Data Analysis**

The data analysis was performed based on Smith, Flowers & Larkin (2012) six steps for conducting an IPA. Initially, the researcher listened to the recorded interviews and read the transcripts. This allowed the researcher to actively engage in the data and in the participants world (Smith, Flowers & Larkin, 2012). In step two, the researcher performed line-by-line reading of the interview while underlining text that appeared to be data of interest. Initial notes and descriptive comments of why the data were of interest was noted continuously. The notes focused on themes that were important to the participants and the meaning they attributed to them. This step allowed the researcher to identify how the participants talked about and thought the subject (Smith, Flowers & Larkin, 2012).

The third step entailed developing emergent themes from the initial notes written during the line-by-line reading. The researcher worked primarily with the initial notes to understand the patterns and connections between them (Smith, Flowers & Larkin, 2012). The researcher developed themes that described the essence and captured an understanding of the specific segment of text that reflected the participants description and the researchers' interpretation (Smith, Flowers & Larkin, 2012). An example of these steps of the coding process is provided

in table 2. In step four, when the emergent themes were established, they were organized in a chronological order. The researcher clustered related emergent themes in groups which resulted in super-ordinated themes with a heading that reflected the theme(s) as a whole. An example of this step is provided in table 3.

Table 2: Example of coding process

Original transcript	Initial notes/ descriptive comments	Emergent theme
<p>I: Har du gjenopptatt de aktivitetene du har holdt på med før? Treffer du venner og familie?</p> <p>D: Det er mindre av det. Det har blitt mindre. Så jeg tror det, jeg var sammen med en gruppe, en gjeng som.. vi møtes hver tirsdag oppå et idrettshus i nærheten her og det var liksom gamle gode kjente fra yngre dager da, men vi har fulgt hverandre nokså mye gjennom idrett. Men det frister ikke noe særlig nå fordi jeg er for dårlig til å komme meg også ser dårlig da. Så det har ikke mer eller mindre stoppa det da foreløpig. Det er jo ikke noe lystig tid fremover nå med vinteren så jeg ser ikke på det som noe fremgang.</p>	<p>Level of activity has decreased.</p> <p>He has stopped participating in his weekly social activity with friends from childhood because of his reduced function and vision impairment.</p>	<p>Impairment after stroke as a barrier to activity.</p>

When these four described steps were completed the researcher had completed a full analysis of one interview transcript. The steps were repeated with all interview transcripts. Smith, Flowers & Larkin (2012) describes step five as a bracketing step between cases. When the researcher moved on to the next case the researcher bracketed ideas and themes from the previous analysis to allow new themes to emerge. The sixth and final step involved finding patterns and connections between all cases. The overview with themes from each case were organized in a chronological order and the researcher looked for connections and differences, as well as which themes seemed to be the most prominent. Themes were reconfigured and relabeled, to create the final result of the analysis.

Table 3: Example of clustering themes

Emergent themes → Super ordinated themes
<p><b>Impairment as a barrier to activity</b></p> <p>Suffering from impairment after stroke</p> <p>Impairment after stroke as a barrier to activity</p> <p>Performing less activities during the day</p>
<p><b>Cognitive impairments</b></p> <p>Challenging to understand cognitive impairments</p> <p>Changes in memory</p> <p>Challenges with communication</p> <p>Lack of energy after stroke</p>

**3.4 Ethical Considerations**

Application to conduct the project was approved by REK (#215391). A letter of information describing the project and what participation entailed was provided for the participant and their spouse to ensure informed consent. Prior to the interview the participant signed a consent form. If the participants spouse wished to participate in the interview, they also signed a consent form. The participants were informed that their consent could be withdrawn without consequences, at any time during the project. The participants personal data and interview transcriptions were anonymized and stored according to current privacy regulations (REK, u.y).



## 4.0 Results

The aim of this study was to explore how people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention. Four semi-structured interviews were conducted and included in the study. The analysis of the data resulted in five main themes: sudden changes in health and function, impairment of cognitive functions and daily life activities, support from family and friends, experiences with receiving occupational therapy and the importance of mastering daily life. Two participants were accompanied by their spouse, whereas the spouse supplemented throughout the interview. The results are mainly based on the participant's statements, however statements from the spouses were included where appropriate to reinforce the participants experiences.

### 4.1 Sudden Changes in Health and Function

Among the participants, three described their experiences regarding stroke and one participant described experiences regarding TBI. However, their experiences had many similarities. All the participants experienced that their life suddenly and unexpectedly changed when they got an ABI. On what seemed to be an ordinary day, their life took a drastic turn. The participants described experiencing a sudden loss of control of their body. This sensation was highlighted as both upsetting and frightening. Symptoms such as difficulties keeping balance, double vision and a cognitive sensation of something unusual going on resulted in emergency admission to the hospital. One participant also described complete memory loss from the onset of the stroke to two weeks after. To this day, the participant still is unable to recall anything from the first two weeks of the rehabilitation.

*“There was something, something very wrong and I had been driving. I parked my car in the garage, it was strange that it happened then. I couldn't climb the stairs, my husband had to assist me up”*

For all the participants their ABI resulted in a lengthy rehabilitation process in their municipality to gradually get back to their daily life at home. At the time the interviews took place, the participants were on different stages. Two participants recently returned back home after staying at the rehabilitation centre, whereas the other two had been home for a longer period of time. In retrospect, training and keeping oneself occupied was seen as the key to acquiring and maintaining cognitive and physical functions in order to live the life they aspired to. One participant expressed that the anger towards the situation contributed to an

internal drive and motivation to keep going. In contrast, one participant described how her optimistic nature provided hope and faith that everything would work out in the end. Another pointed out that, whatever in life you want to be good at, you have to practice performing that activity. Whether it be doing homework to achieve good grades in school or training to reach your goals during rehabilitation. Similarly, the last participant stated that you need to assess where you are and how you should move forward.

#### **4.2 Impairment of Cognitive Functions and Daily Life Activities**

Sustaining an ABI resulted in multiple cognitive and bodily changes that affected the participants daily life activities. The extent of the sequels from the ABI varied between the participants. Some changes seemed to be less troublesome with time and rehabilitation, others were persistent over time. Initially, the participants had some trouble explaining the cognitive impairments they were experiencing when they were asked. They became hesitant to answer or unsure of how to describe it, often continuing to describe physical impairments. However, during the interviews various cognitive impairments were expressed. As a result from the ABI, three out of four participants was more tired and had an increased need for rest during the day and after strenuous activities. Especially after cognitive demanding activities. One participant expressed that in general, all daily life activities were more demanding than they used to be. Another participant explained that performance of activities took longer time. The participant who didn't notice changes in level of energy was grateful that she was able to perform activities without having to lay down to rest afterwards as she had heard fatigue was a common sequel to ABI.

The participants experienced cognitive impairment related to vision, language and communication skills, memory and attention. The changes in function became evident when they began to resume daily life activities. When they performed activities they previously had mastered, they weren't able to perform the activity in the same way they did prior to the ABI. Additionally, the performance was influenced by an uncertainty of their abilities and what they could master with their cognitive changes. For example, one participant described that she always forgot one item on her shopping list which required her to back a second time, and experiencing trouble scanning the shelves for the items she needed. Another participant explained that she no longer mastered large social happenings. Her double vision made it

difficult to get an overview of the room and could make her dizzy. In addition, one participant explained difficulties getting safely into bed due to his impaired vision.

The participants discussed how impairment of cognitive functions resulted in loss of meaningful activities. The ability to effectively communicate with family were challenging due to expressive aphasia for one participant. The participant tried to practice his speech, but the spouse described a significantly quieter partner. Nevertheless, the participant mentioned that he tried to make himself understood when he spoke. One participant described how she had tried to get her drivers' license back after the ABI but was forced to give up driving when she failed the required cognitive tests several times. Another participant also mentioned the loss of her driving licence, which made her more dependent on her husband for transport as the public transport services in her area was sparse. Also, the combination of both physical and cognitive impairments was a barrier to resume social activity. One participant described how his reduced balance and impaired vision affected his desire to continue his routine meeting up with close friends:

*“I participated in a group, a group that.. we meet up every Tuesday at a sports hall nearby and it's with friends I have known since my younger days. We kept in close contact through sports. But, it's not tempting to go now because I am too frail and my vision is impaired. So, I more or less stopped participating for the time being”*

### **4.3 Support from Family and Friends**

An important source of emotional support and assistance for the participants was their family and friends. During a time of uncertainty and changed cognitive and bodily functions the participants relied on their close relationships during and after treatment and rehabilitation. Family and friends were key contributors to achieving a meaningful life that allowed them to perform wanted and necessary daily life activities. Their loved ones had the role of support system, helper and an extension of their own body when their functional abilities constricted performance. One participant described valuable help from her daughter who provided assistance with shopping, transportation to activities and assistance with different technology. Also, one participant described how his spouse helped him practice his mobility with a walker as his impaired vision made it difficult to train on his own. Another participant managed to continue her daily walks by walking arm in arm with her husband when her double vision restricted her possibility to go for walks independently during the winter. Their family and

friends contributed to maintaining motivation throughout rehabilitation, as a participant described that the rehabilitation process would be much harder if she had to go through it alone. The participants spouses were in general described as important contributors to mastering daily life activities, especially in activities where their cognitive and physical changes limited performance. One of the participants spouse explained how they coped with daily life after the participant returned home from the rehabilitation centre:

*“He’s been home since Monday and.. we make it work by collaborating. It is an inconvenient apartment. But we have managed without home nursing care. We manage to get by the two of us in a way.”*

#### **4.4 Experiences with Receiving Occupational Therapy**

All participants expressed great gratitude for receiving occupational therapy during their rehabilitation. Three participants had received occupational therapy in the rehabilitation centre and their home. One participant had only received occupational therapy in the rehabilitation centre at the time of the interview. However, the OT from the rehabilitation centre had visited the participants home at several occasions. Several occupational therapy assessment and interventions were described by the participants. Conversations about daily life, activities, family and social networks was described as a measure the OT used to get to know the participants more in the beginning and throughout their rehabilitation. Further, being observed by the OT during performance of daily life activities was mentioned by all the participants. Activities such as personal hygiene, getting dressed, cooking and mobility were assessed in order to regain independence, boost or ensure safe performance. The observations and following interventions were firstly conducted in the rehabilitation centre and later on in their own homes. Most of the participants were comfortable with being assessed and observed while performing activities and tasks as they knew it was helpful in order to get better. However, one participant described her experience with being observed by the OT while cooking in the rehabilitation centres’ training kitchen as stressful and frustrating. The session made her feel like a child when she was being observed. Cooking had become both cognitively and physically demanding:

*“We were in a training kitchen. And I was supposed to do it all by myself. It was so difficult. I have been working as a kitchen manager for many years. It was no fun at all”*

Different interventions were applied to enable the participants to master the activities the participants wanted and needed to do. Practicing performing specific activities was helpful in order to be more confident and learn new ways or adapted ways to perform them. For example, one participant described how the OT practiced taking the bus with her so she would feel safe doing it again herself. Additionally, strategies aiming to compensate for lost ability or function were incorporated to improve performance. A strategy for getting in bed safely and independently with reduced vision was taping guidelines on the mattress to ensure that the participant got into the bed in the right place. Cognitive rehabilitation targeting specific cognitive functions such as vision, memory and attention through games and cognitive desktop tests was mentioned by two participants. One participant mentioned doing the same desktop test twice, with several weeks between the tests. When retaking the test, the results had improved which increased her motivation as it showed improvement and effect from the interventions. Also, getting exercises and tasks to complete between visits from the OT was mentioned as an important part of staying active and structuring time for one participant. This prevented the days and rehabilitation process as a whole from becoming long and unmanageable. Compensatory measures such as walking aids were also provided by the OT for several of the participants. In addition to occupational therapy specific assessment and intervention, it was described that the OT provided emotional support and someone to confide in and discuss their situation with.

Prior to sustaining an ABI and receiving rehabilitation services in their municipality the participants described limited knowledge of what occupational therapy was and what an OT can do. All of the participants found it difficult to differentiate occupational therapy versus physical therapy explaining that they first thought the two occupational groups performed similar tasks. One participant described how he understood the differences between the two occupations by explaining that the PT focused on physics and bodily movement, whereas the OT was more concerned with how the activity were performed. Throughout their work with the OT, the participants became more aware of the OTs aim to enable independence and mastery of daily life activities. OTs was described as a “new” health care professional to one participant who mainly thought of nurses and nursing assistants when she thought of health care. The OTs function was thought of as unique because of how they assisted the participants to regain independence and previous daily life activities in the rehabilitation centre, in their home and their community. In conclusion, one participant described their experience like this:

«... I am happy that I got to know an occupational therapist.»

#### **4.5 The Importance of Mastering Daily Life**

All the participants expressed that the goal and wish for rehabilitation was to get back to their previous function. A consistent theme was that the participants wanted to master their previous roles, habits and routines. They wanted to reclaim their daily life activities. The participants described how performing the activities they needed and wanted to do brought them happiness and feeling of mastery, and also was a motivational factor in their rehabilitation process. All the participants spoke highly of their stay in hospitals and rehabilitation centres, however being able to return to their home and local environment was important to them all. One participant described how he could feel changes in his body and how it affected his motivation to continue practicing activities:

*“It becomes a habit. The more you practice, the more you can feel improvement in your body.  
In the end it becomes enjoyable”*

The participants daily life consisted of activities they wanted and needed to do, as well as activities they performed alone and together with family or friends. Being able to perform these activities in their home and community was considered meaningful. This included learning to administer their own medicine, getting into bed independently, cooking their own meals and walking safely with a mobility aid. Further, utilizing their local environment by mastering taking the bus on their own, attending the library and going for walks in the neighbourhood was considered important by the participants. The cognitive impairments required the participants to adapt and find new ways to perform certain activities. Or find alternative activities they could enjoy. For example, going for a walk in the neighbourhood when a walk in the woods became too challenging, meeting friends in smaller groups rather than large gatherings or listening to audio books when reading became impossible due to vision impairment. Adapting the activity didn't erase their longing for the previous activity, but it still provided a sense of mastery and joy. One participant described how shovelling snow gave her a sense of confidence and mastery:

*“I thought about it earlier when I was shovelling snow down to the bird feeder, you wouldn’t have thought that I have had a stroke. So, I was very satisfied with that”*

The two male participants expressed that they weren’t as social as previously and stayed more at home after acquiring their ABI. Leaving the house and being socially active were challenging due to their cognitive impairment, such as speech and vision. However, the two female participants highlighted the importance of mastering social activities with family and friends despite cognitive and functional changes. Being able to have family and friends over for dinner or just a visit brought them happiness. Also, going over to family or friends house allowed them to get out of their house which was meaningful to them. One of them described the importance of meeting family and friends this way:

*“I notice that when I have visitors during the weekend and such, I get some extra energy”*

Throughout the rehabilitation process and practicing activities, the participants gradually noticed improvements in their performance. From being heavily dependent on help in the early stages of their rehabilitation, the participants slowly became more independent and less dependent on health care workers. However, the participants described being in need of assistance to some degree in several daily life activities and it being all right as they felt in control of their own life. The level of independence and subjective feeling of how satisfied they were with performance of activities seemed to be related to time since their ABI occurred. One participant explained that she would ask her spouse for help or to perform daily life activities for her when she first returned home. Despite that, she was focused on being independent and asked less for help as she felt more comfortable. With time and practice independence came gradually for the participants. A spouse explained the participants progress in this way:

*“... you went from not being able to hold the deodorant yourself, to being able to put deodorant on. And getting dressed, brushing your teeth and general personal hygiene”*

## **5.0 Discussion**

The aim of this master project was to explore how people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention. In this chapter the findings are discussed in light of the theoretical framework and previous research. The discussion is structured according to the three components of SOC: comprehensibility, manageability and meaningfulness. The structure is chosen in order to highlight each component of SOC influence on doing, being, belonging and becoming.

### **5.1 Comprehensibility: Coming to Terms with Unexpected Changes**

Results from this study shows that unexpected illness and change in cognitive and bodily function causes a sense of not being in control, which was regarded as a frightening and upsetting experience. Suddenly, the participants experienced being in need of assistance in activities, both in the acute stages and when returning to daily life. In salutogenesis, comprehensibility refers to how a person experience internal and external stimulus (Antonovsky, 2012). The stimulus might be regarded as chaotic, unexpected and incomprehensible, or it could be understandable and clear information (Antonovsky, 2012). Results similar to this study, have been reported in previous research where participants have expressed how sustaining an ABI and experiencing cognitive impairment can be life changing and how it influences and alters peoples' activities (Erikson, Karlsson & Tham, 2016; Kapoor et al., 2017; Pappadis et al., 2019). Further, adapting to a new life with ABI is reported to be overwhelming and frightening (Erikson et al., 2007). These findings highlight the major and extensive impact sudden and unexpected illness and disability has in peoples' lives. Moreover, the sudden changes seem to impact the participants in this study level of comprehensibility (Antonovsky, 2012), as well as doing and being (Wilcock & Hocking, 2015). What people are doing can depend on multiple factors (Wilcock & Hocking, 2015), for example disease or disabilities. The stimulus the participants were experiencing in the acute stages of their ABI was chaotic and incomprehensible. Additionally, the participants changed function affected their doing and being as they were forced to change performance activities due to impairment, which affected their sense of self.

According to previous research, cognitive impairments can be challenging to understand and difficult to describe (Maskill & Tempest, 2017). In contrast, physical impairments have received considerably more attention within research and is a considered a key element in



assessment and intervention during rehabilitation after ABI (Kapoor et al., 2017; Pappadis et al., 2019). The participants in this project described their bodily experiences and physical impairments clearly. However, when the researcher specifically asked about the cognitive impairments they were experiencing, the participants became unsure of what to answer or how to describe it. Often continuing to describe bodily changes. Several studies point out the need for greater emphasis to be placed on cognitive function and impairments in health care services (Helse- og omsorgsdepartementet, 2017; Kapoor et al., 2017; Pappadis et al., 2019). The physical disabilities described by the participants in this study could be classified as mild to moderate and might be considered as good clinical outcome based on the research by Kapoor et al (2017). Interestingly, the participants still reported cognitive impairments that negatively affect their daily life activities. This result is coherent with previous studies that highlights the fact that cognitive impairment is present in patients with no or minor physical disabilities (Jokinen et al., 2015). The result from this study may indicate that cognitive impairments are challenging to comprehend, and as previous research have stated, difficult to describe for people experiencing them. Within salutogenesis it is believed that in order to increase peoples' comprehensibility the information they receive from external stimulus needs to be clear, cohesive and understandable (Antonovsky, 2012). Before mobilizing resources to handle the situation it is necessary for the person understand the scope and consequences of the issue (Antonovsky, 2012). A person with a strong SOC will then continue to structure information and find a solution to the situation (Antonovsky, 2012). The result from this study could imply that increased focus and research on cognitive impairment can contribute to increasing the persons' comprehensibility and thus their ability to find a suitable solution to the situation (Antonovsky, 2012). Which also supports the assumption that cognitive impairments require more attention within rehabilitation. Considering previous studies have reported that people with ABI experience cognitive challenges that affects their activities 11-13 years after injury (Eriksson, Karlsson & Tham, 2016), it is necessary to develop effective measures to increase comprehensibility regarding cognitive impairment and to ensure activity and participation for this group.

Despite difficulties describing specific cognitive impairments, the participants in this study reflected on how cognitive impairments affected their life and what they needed to do in order to reach their goals. Which proves the participants, despite cognitive impairment is aware of, can describe and reflect upon these changes and how it has affected their activities. This should be taken into account when assessing if patients with cognitive impairment are eligible

to participate in research. A person with cognitive impairment is able to describe their thoughts, wishes and needs. In this study, all the patients emphasized the importance of engaging in rehabilitation and occupational therapy in order to maintain and acquire cognitive and physical functions. As well as assessing where you stand and mobilizing an internal drive to get back to daily life. This is interesting as Pappadis et al. (2019) found that some participants became depressed and isolated themselves from others. Further, research shows that longing for previous life and activities could feel like an unattainable goal (Erikson, Karlsson & Tham, 2016). This could imply that the participants in this study have a high sense of comprehensibility (Antonovsky, 2012), which seem to be an enabling factor in regard to continuing doing activities, as well as motivation to continue being and becoming through doing (Wilcock & Hocking, 2015). Through doing daily life activities and participating occupational therapy interventions, the participants become more knowledgeable of themselves and their newfound situation, as well as gradually developing a new or altered sense of being (Wilcock & Hocking, 2015). Therefore, the results from this study can indicate that a high sense of comprehensibility (Antonovsky, 2012) positively influences being and becoming through doing (Wilcock & Hocking, 2015) for people experiencing cognitive impairment after ABI.

## **5.2 Manageability: Learning to Manage Daily Life Activities with Cognitive Impairment**

The participants in this study described several resources that impacted their ability to manage their daily life with cognitive impairment and ABI. One resources they all described, which was an important factor contributing to their level of manageability, was their internal motivation to adapt to the circumstances and work towards their goals. They were able to view the situation as something they could influence and manage with their resources. Within salutogenesis, manageability refers to a person's ability to handle unexpected life events and how a person locates and utilize informal and formal resources that are available to them (Antonovsky, 2012). GRR are factors that facilitate protection or a response when encountering stressors and challenging situations in life (Antonovsky, 2012). This could be GRR such as self-esteem, social support, knowledge and housing (Bhattacharya et al., 2020). Previous research has shown that sudden disease and impairment can cause disruption in relationships and social loss (Erikson et al., 2016). For others, family and friends are important contributors to safety, continuity and a sense of belonging (Erikson, Karlsson &

Tham, 2016). The participants in this study expressed how their family and friends provided assistance and emotional support when they experienced changes in their daily life activities due to cognitive and physical impairments. Two of the participants in this study described being less in contact with their friends and staying more at home with their family. In contrast, the two participants who regularly met up with their friends described being more active and energized. According to Wilcock & Hocking (2015), relationships to people or communities are created through activities and belonging is associated with meaning, happiness and security in relationships. Additionally, being reflects a persons' identity and sense of self through the activities they perform (Wilcock & Hocking, 2015). In light of this, the results from the study indicate that friends and family seemed to be an GRR (Antonovsky, 2012) that influenced their level of manageability and being and belonging through doing (Wilcock & Hocking, 2015) as it increased their level of activity by performing activities together, as well as they provided emotional support and assistance.

Following the implementation of the Norwegian Coordination Reform, the municipalities have greater responsibilities to enable people to live in their own home and perform daily life activities in their local environment (Ness & Horghagen, 2020). Within salutogenesis, housing is an important GRR (Antonovsky, 2012; Bhattacharya et al., 2020) and all the participants in this study wished to return home after staying in the hospital and municipal rehabilitation center. Their home was an important arena for doing and being, but also belonging (Wilcock & Hocking, 2015) as all the participants shared a home with their spouse and it was described as a significant arena for daily life activities. Previous research has found that the most frequently provided intervention by Norwegian OTs working in the municipality were environmental modification and implementation of assistive devices (Stigen et al., 2022). This became evident as all the participants in this study had received one or more home visits from an OT working at the rehabilitation center or in the municipal OT service before returning to their home. During the home visits the OT assessed whether their home was suitable and safe, or whether adaptations were needed. People with cognitive impairment after ABI have reported challenges with mastering new and former activities (Erikson et al., 2007). Also, changing preferences and habits could be challenging (Häggström & Larsson Lund, 2008). Considering the previous research, the results from this study could imply that being able to return to their own home increased the participants sense of manageability (Antonovsky, 2012). They were able to return to a place where they feel comfortable and have well-established habits and routines. Being in a familiar environment could make it

easier to resume habits, roles and activities, thus having a positive influence on being and belonging through doing when returning to daily life (Wilcock & Hocking, 2015).

Prior to sustaining an ABI and cognitive impairment, the participants in this study had no experiences with receiving occupational therapy services. The OT was described as an unfamiliar health care profession to the participants and they had some trouble differentiating occupational therapy from physical therapy. As mentioned, OTs core competencies are enabling activity and participation, regardless of diagnosis or functional level (Norsk Ergoterapeutforbund, 2017). OTs have knowledge of how cognition relates to performance of activities, and can implement effective interventions (AOTA, 1999). Previous research has found that OTs working in municipalities utilize standardized and non-standardized methods, and a mix of both when working with persons with cognitive impairment (Holmqvist, Kamwendo & Ivarsson, 2009; Stigen, Bjørk & Lund, 2019). The participants in this study described several assessments and interventions they had participated in with the OT. They mentioned having conversations about their daily life, being observed while performing activities and completing desktop tests. Participating in the assessment were appreciated by the participants as this meant they had the opportunity to gain knowledge of their impairment and continue their development. According to salutogenesis, if a person has a strong sense of manageability and appropriate resources available, they are motivated and able to cope (Antonovsky, 2012). Participating in occupational therapy seemed to increase the participants sense of manageability as they got a clearer picture of how cognitive impairment affected their performance of activities and thus facilitated being and becoming through doing (Wilcock & Hocking, 2015) when interventions were initiated in order to improve performance of activities.

An OT intervention can target the persons skills, adapting the activity or make changes in the environment to enhance or maintain function and independence (AOTA, 1999). However, OTs working with this group of people have expressed an uncertainty and lack of sufficient knowledge in their practice concerning cognitive impairment and ABI (Holmqvist, Kamwendo & Ivarsson., 2009; Stigen, Bjørk & Lund, 2018). Still, the participants in this study described several interventions they benefited from. This included practicing specific skills with games or cognitive desk top tests, utilizing strategies to enhance performance of activities or adapting the activity. Also, having a training program or tasks to perform in between visits from the OT was mentioned as a good way of structuring the day and to stay

active. The results may suggest that occupational therapy interventions increased their level of manageability (Antonovsky, 2012) and encouraged doing (Wilcock & Hocking, 2015). Through occupational therapy the participants were supported to regain a meaningful life through the use of training, strategies, adaption of activities and knowledge of their impairments and their effect on performance. Being able to learn and utilize different tools to master activities seemed to facilitate being and becoming through doing (Wilcock & Hocking, 2015). Which further supports the statement arguing that OTs are an essential health care profession when assisting people with cognitive impairment create or maintain meaningful lives in their environment (AOTA, 1999).

With the demographic shift towards an older population in large parts of the world (FHI, 2022; WHO, 2022) and the expected increase of ABI and cognitive impairments (Hyder et al., 2007; Murman, 2015; Helse- og omsorgsdepartementet, 2017), there is an substantial need for research regarding peoples´ experiences living with cognitive impairment after ABI and which OT assessments and interventions effectively enable participation in meaningful activities. The research is necessary to increase manageability (Antonovsky, 2012) and being, belonging and becoming through doing (Wilcock & Hocking, 2015), for both patients and OTs. Findings from this study can be seen in connection with Antonovskys´ (2012) theory that a combination of formal and informal GRR, as well as how a person is able to utilize the resources influences the ability to manage stressors in life and level of SOC. Furthermore, access or lack of GRR (Antonovsky, 2012) appear to influence the ability to continue being, belonging and becoming through doing (Wilcock & Hocking, 2015), after acquiring cognitive impairment and ABI.

### **5.3 Meaningfulness: Experiencing Meaningfulness in New Ways of Doing Activities**

According to Wilcock & Hocking (2015) doing refers to all the activities people perform and participate in. Furthermore, through activities people create and maintain their identity (Christiansen, 1999). Additionally, doing activities is closely linked to being which reflects peoples´ roles and interests (Wilcock & Hocking, 2015). The participants in this study expressed that the goal of their rehabilitation process was to get back to their previous function and daily life activities, which was also an important motivational factor. This seems

to be an instinctive goal of people who participate in rehabilitation after ABI as several studies report similar findings (Erikson et al., 2007; Erikson, Karlsson & Tham, 2016). The results from this study supports the theory that the activities people are doing is closely linked to being (Wilcock & Hocking, 2015). This might explain the need to resume previous activities as it is such an important part of how we perceive ourselves. Moreover, participants in this study highlighted the importance of mastering daily life activities, and how performing the activities brought them a sense of mastery and happiness. Activities are thought to be essential for peoples´ health and well-being and engaging in activities allows people to discover meaning in life (Christiansen & Townsend, 2010; Jarman, 2010; Law, 2002; Wilcock, 1993). The results suggest that being able to perform daily life activities is regarded as meaningful and act as a motivational factor that facilitates commitment to regaining independence and resuming daily life activities, and therefore increased being and becoming through doing (Wilcock & Hocking, 2015).

As defined in salutogenesis, meaningfulness describes whether life is meaningful and emotionally comprehensible (Antonovsky, 2012). Further, meaningfulness involves whether challenges encountered in life is perceived as worth committing to and working through (Antonovsky, 2012). The result from this study described how the participants activities and participation had changed after sustaining an ABI and cognitive impairment. However, they had learned to adjust performance of various activities to their function and capacity. Even if they couldn´t perform activities how they previously had preferred and performance of the activity had changed, the activities was still regarded as meaningful. Adaptions described by the participants in this study was listening to audiobooks as a compensation for not being able to read or meeting friends in smaller groups when large gatherings became overwhelming. Similar finding has been reported in previous studies describing that giving up preference and habits are challenging (Häggström & Larsson Lund, 2008). Nevertheless, finding new ways to perform activities positively influenced participation when activities couldn´t be perform like they used to (Häggström & Larsson Lund, 2008). Also, doing activities alone or with others leads to various forms of becoming on multiple levels (Wilcock & Hocking, 2015). By adapting activities that were considered meaningful to the participants they could continue to perform activities alone or with others that were in line with their identity, roles and interest, which could be a preventative factor against inactivity and isolation. Therefore, being able to perform activities that were important to them positively influenced being, belonging and becoming through doing (Wilcock & Hocking, 2015) and increased their sense of

meaningfulness (Antonovsky, 2012). In contrast to this, findings from previous studies have described that being unsuccessful in adapting meaningful activities could lead to loss of the activity or reduced engagement (Häggström & Larsson Lund, 2008).

Findings from this study revealed that a sense of meaningfulness appeared to be a significant factor in regard to rehabilitation and occupational therapy assessment and intervention. Targeting activities the participants considered important and meaningful during assessment and intervention were an essential source for motivation. This applied to both activities they needed to do and activities they wanted to do. For example, being independent in personal care, meeting friends or independently utilizing public transport. Seeing progress in performance of activities they perceived as meaningful facilitated the drive to keep engaging in rehabilitation. As described, the goal of occupational therapy is performance and participation in activity (Norsk Ergoterapeutforbund, 2017). Moreover, activity is regarded as a means to improve cognitive, communicative and sensorimotor skills (Norsk Ergoterapeutforbund, 2017). OTs in previous studies have highlighted their use of activities as a means in assessments and interventions, but more importantly they have specified that one of the first questions they asked patients were “what is meaningful for you?” (Stigen, Bjørk & Lund, 2019).

The result from this study highlight the importance of considering which activities that are meaningful to each individual and that level of meaningfulness is an important factor in achieving successful occupational therapy assessment and interventions. Focusing on activities that are meaningful to the person will bring motivation and engagement to participate in assessments and interventions, as well as seeing that participation in meaningful activities is possible in spite of ABI and cognitive impairment. This could lead to increased motivation and commitment to participating in rehabilitation. Also, highlighting that the effort they put towards rehabilitation to achieve their goals will be worth it (Antonovsky, 2012). Therefore, both experiencing a sense meaningfulness (Antonovksy, 2012) in daily life and being, belonging and becoming through doing meaningful activities (Wilcock & Hocking, 2012), appeared to have a mutual influence on each other, as well as facilitating a meaningful life with cognitive impairment after ABI.

## **6.0 Conclusion**

The aim of this study was to explore how people with ABI experience cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention. Despite experiencing sudden changes in health and disability that caused severe changes in life and their performance of activities, the participants were able to reflect on their situation and mobilize internal motivation to take action. The results highlight how various GRR are valuable after sustaining an ABI and experiencing cognitive impairment. This included internal motivation, support from family and friends and being able to return to their home and performing daily life activities. Through occupational therapy assessment and interventions which focused on activities that were meaningful to them, they gradually resumed their daily life activities. A central factor that influenced the participants' motivation and desire to regain their lives were meaningfulness, both in daily life activities and when participating in occupational therapy intervention and assessment. Experiencing that daily life could be filled with meaningful activities was necessary to embrace life with cognitive impairment after ABI.

According to salutogenesis, if a person with a strong SOC meets a stressor they will most likely: understand the challenge (comprehensibility), believe they have the resources to cope (manageability) and be motivated or wish to cope (meaningfulness) (Antonovsky, 1996). In light of this, the results presented from this study suggest that a strong SOC (Antonovsky, 2015), positively influence being, belonging and becoming through doing meaningful daily life activities (Wilcock & Hocking, 2015) with cognitive impairment after ABI. Therefore, it is important to increase knowledge of cognitive impairment and ABI, enable people to locate and utilize formal and informal resources, as well as providing occupational therapy assessment and interventions based on what is considered as meaningful activities to each individual.



## **7.0 Strengths and Limitations**

This study describes four participants with ABI experiences with cognitive impairment in daily life activities and participation in occupational therapy assessment and intervention thoroughly. The participants represent both genders which could highlight potential similarities or differences between them. However, in order to ensure generalisability and for the results to be representative for people experiencing cognitive impairment after ABI, a larger sample size would be needed. Nevertheless, this project could increase knowledge of the subject and facilitate further research. During recruitment of participants, some challenges were encountered that might have affected the sample size. The OTs who represented their respective municipality and referred eligible participants to this project had to leave for other obligations. This might have affected the referral of participants to the project as new OTs had to familiarize themselves with the project's aim and inclusion criteria. Further, conducting research regarding people with cognitive impairment requires careful assessment of the persons' ability to give true informed consent and input on the subject of the study. Therefore, the inclusion criteria were quite strict. By expanding the inclusion and exclusion criteria, the sample size could have increased. In addition, the results might have been affected as it could have led to inclusion of participants with a greater range of difficulties related to cognitive impairment.

Throughout the work with this project, the researcher has been conscious of how her role as a researcher and her pre-understanding of the topic from her own work as an OT could influence the research process and ultimately the results. The researcher had limited experience with conducting qualitative research in advance. In terms of interviews, the researcher's limited experience could have affected the formulation of questions or how follow-up questions were asked which could negatively affect the participants' answer or ability to understand the question. Also, a limitation could be the difference in execution of interviews, whereas two were conducted digitally. Considering the target group of the study, face-to-face interviews are advantageous as digital interviews can lead to misunderstandings or unclear communication. Also, having to master digital devices prior and during the interview could have caused additional stress for the participants. During coding and creating themes, the transcript and the participants' statements were translated from Norwegian to English. This could have affected the meaning or interpretation of the participants' answers. Also, since the researcher hasn't conducted much data analysis prior to this study she might have missed themes in the material a novel researcher could have noticed. The analysis may have been

strengthened by more researcher participating in the analysis, but this was not possible due to the scope of the study. To ensure valid results that stay as close to the participants experiences, IPA was chosen when conducting analysis of data and “bracketing” were consistently utilized during this process.

## **8.0 Implications for Future Research**

In order to increase research and knowledge of cognitive impairment after ABI and occupational therapy services, there is a need for more and larger studies from both a qualitative and quantitative perspective. Future research should seek to described peoples experience with cognitive impairment in depth. Also, research should focus on peoples experience regarding what is perceived as effective assessments and interventions to them. In addition, future research could focus on increasing knowledge of cognitive impairment and how information about impairment of cognitive functions are communicated to people who are affected in order to increase comprehensibility. There is also a need for more research on how and which occupational therapy assessments and interventions can facilitate activity and participation for this group. This information would be useful to both OTs, but also other health care professions working with cognitive impairment and ABI. Increased research on the topic will contribute to knowledge and hopefully make assessment and interventions focusing on cognition an integral part of rehabilitation after ABI, both in the acute and chronic stages of rehabilitation.

## References

- American Occupational Therapy Association. (1999). Management of Occupational Therapy Services for Persons With Cognitive Impairments (Statement). (*The American Journal of Occupational Therapy*, 53(6), 601–607. <https://doi.org/10.5014/ajot.53.6.601>)
- Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, 11(1), 11–18. <https://doi.org/10.1093/heapro/11.1.11>
- Antonovsky, A., & Sjøbu, A. (2012). *Helsens mysterium: Den salutogene modellen*. Oslo: Gyldendal akademisk.
- Atchinson, B. & Dirette, D.K. (2007). *Conditions in occupational therapy: effect on occupational performance* (3<sup>rd</sup> ed.). Lippincott Williams & Wilkins.
- Bhattacharya, S., Pradhan, K., Bashar, M., Tripathi, S., Thiyagarajan, A., Srivastava, A., & Singh, A. (2020). Salutogenesis: A bona fide guide towards health preservation. *Journal of Family Medicine and Primary Care*, 9(1), 16–19. [https://doi.org/10.4103/jfmpe.jfmpe\\_260\\_19](https://doi.org/10.4103/jfmpe.jfmpe_260_19)
- Chiavaroli, F., Derraik, J. G. B., Zani, G., Lavezzi, S., Chiavaroli, V., Sherwin, E., & Basaglia, N. (2016). Epidemiology and clinical outcomes in a multicentre regional cohort of patients with severe acquired brain injury. *Disability and Rehabilitation*, 38(20), 2038–2046. <https://doi.org/10.3109/09638288.2015.1111439>
- Christiansen, C.H. (1999). Defining Lives: Occupation as Identity: An Essay on Competence, Coherence and the Creation of Meaning, 1999 Eleanor Clarke Slagle Lecture. *American Journal of Occupational Therapy*, 53(6), 547-558.
- Christiansen, C.H & Townsend, E. (2010). An Introduction to Occupation. I C.H.Christensen & E.Townsend (Red.), *Introduction to Occupation: The Art and Science of Living* (p.1 – 34). Pearson Education.
- Deary, I. J., Corley, J., Gow, A. J., Harris, S. E., Houlihan, L. M., Marioni, R. E., Penke, L., Rafnsson, S. B., & Starr, J. M. (2009). Age-associated cognitive decline. *British Medical Bulletin*, 92(1), 135–152. <https://doi.org/10.1093/bmb/ldp033>
- Douiri, A., Rudd, A. G., & Wolfe, C. D. A. (2013). Prevalence of poststroke cognitive impairment: South London stroke register 1995-2010. *Stroke* (1970), 44(1), 138–145. <https://doi.org/10.1161/STROKEAHA.112.670844>
- Erikson, A., Karlsson, G., Borell, L., & Tham, K. (2007). The Lived Experience of Memory Impairment in Daily Occupation after Acquired Brain Injury. *OTJR (Thorofare, N.J.)*, 27(3), 84–94. <https://doi.org/10.1177/153944920702700302>

- Erikson, A., Karlsson, G., & Tham, K. (2016). Living with the long-term consequences 11-13 years after stroke: A phenomenological study. *Journal of Rehabilitation Medicine*, 48(10), 847–852. <https://doi.org/10.2340/16501977-2161>
- Folkehelseinstituttet. (2022, 17. June). *Folkehelse rapporten – Helse hos eldre i Norge*. <https://www.fhi.no/nettpub/hin/grupper/eldre/#livskvalitet>
- Gramstad, A., & Nilsen, R. (2017). Prioritized topics for research amongst Norwegian occupational therapists. *Ergoterapeuten*, 60(3), 36-45.
- Gutiérrez Pérez, C., Sävborg, M., Pählman, U., Cederfeldt, M., Knopp, E., Nordlund, A., Åstrand, R., Wallin, A., Fröjd, K., Wijk, H., & Tarkowski, E. (2011). High frequency of cognitive dysfunction before stroke among older people. *International Journal of Geriatric Psychiatry*, 26(6), 622–629. <https://doi.org/10.1002/gps.2573>
- Häggström, A., & Lund, M. L. (2008). The Complexity of Participation in Daily Life: Qualitative Study of the Experiences of Persons with Acquired Brain Injury. *Acta Dermato-Venereologica*, 40(2), 89–95. <https://doi.org/10.2340/16501977-0138>
- Helse- og omsorgsdepartementet. (2017). *Nasjonal Hjernehelsetrategi (2018-2024)*. [https://www.regjeringen.no/contentassets/8eba3248e9e843f6b09e97a84a97a153/hjernehelsetrategi\\_2018-24\\_121217.pdf](https://www.regjeringen.no/contentassets/8eba3248e9e843f6b09e97a84a97a153/hjernehelsetrategi_2018-24_121217.pdf)
- Helsenorge. (2020). *Hjerneskode hos voksne*. Retrieved 22. April from <https://www.helsenorge.no/sykdom/hjerne-og-nerver/hjerneskode-hos-voksne/>
- Holmqvist, K., Kamwendo, K., & Ivarsson, A.-B. (2009). Occupational therapists' descriptions of their work with persons suffering from cognitive impairment following acquired brain injury. *Scandinavian Journal of Occupational Therapy*, 16(1), 13–24. <https://doi.org/10.1080/11038120802123520>
- Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation (Reading, Mass.)*, 22(5), 341–353. <https://doi.org/10.3233/nre-2007-22502>
- Jarman, J. (2010). What is occupation? Interdisciplinary Perspectives on Defining and Classifying Human Activity. I C.H.Christensen & E.Townsend (Red.), *Introduction to Occupation: The Art and Science of Living* (p.59 – 77). Pearson Education.
- Jin, K., Simpkins, J. W., Ji, X., Leis, M., & Stambler, I. (2015). The Critical Need to Promote Research of Aging and Aging-related Diseases to Improve Health and Longevity of the Elderly Population. *Aging and Disease*, 6(1), 1–5. <https://doi.org/10.14336/ad.2014.1210>

- Jokinen, H., Melkas, S., Ylikoski, R., Pohjasvaara, T., Kaste, M., Erkinjuntti, T., & Hietanen, M. (2015). Post-stroke cognitive impairment is common even after successful clinical recovery. *European Journal of Neurology*, 22(9), 1288–1294.  
<https://doi.org/10.1111/ene.12743>
- Kapoor, A., Lanctôt, K. L., Bayley, M., Kiss, A., Herrmann, N., Murray, B. J., & Swartz, R. H. (2017). "Good Outcome" Isn't Good Enough: Cognitive Impairment, Depressive Symptoms, and Social Restrictions in Physically Recovered Stroke Patients. *Stroke* (1970), 48(6), 1688–1690. <https://doi.org/10.1161/STROKEAHA.117.016728>
- Katz, N., & Hadas, N. (1995). Cognitive Rehabilitation: Occupational Therapy Models for Intervention in Psychiatry. *Psychiatric Rehabilitation Journal*, 19(2), 29–36.  
<https://doi.org/10.1037/h0095443>
- Kristensen, H.K. & Birkmose, D. (2013). Kognitive vanskeligheder. I E.E. Wæhrens, A. Winkel & H.S Jørgensen (Red.), *Neurologi og Neurorehabilitering* (2<sup>nd</sup> edition, p. 93-109). Munksgaard.
- Kvale, S. & Brinkmann, S. (2015). *Det kvalitative forskningsintervju*. Gyldendal akademisk.
- Law, M. (2002). Participation in occupations of everyday life. *The American Journal of Occupational Therapy*, 56 (6), 640-649.
- Lindstad, M.Ø., Obstfelder, A. U., Sveen, U., & Stigen, L. (2022). Effectiveness of the Perceive, Recall, Plan and Perform intervention for persons with brain injury in community-based rehabilitation: protocol for a single-case experimental design with multiple baselines. *BMJ Open*, 12(10), e060206–e060206.  
<https://doi.org/10.1136/bmjopen-2021-060206>
- Maskill, L. & Tempest, S. (2017). *Neuropsychology for Occupational Therapists: Cognition in Occupational Performance* (4<sup>th</sup> edition). Wiley Blackwell.
- Murman, D.L. (2015). The Impact of Age on Cognition. *Seminars in Hearing*, 36(3), 111–121. <https://doi.org/10.1055/s-0035-1555115>
- Ness, N.E, & Horghagen, S. (2020). Occupational Therapy in Norway: Influence of the Nordic Welfare State Policy and the Professional Development of Occupational Therapy and Occupational Science Worldwide. *Annals of International Occupational Therapy*, 4 (1), 35-43. <https://journals.healio.com/doi/epdf/10.3928/24761222-20200413-04>
- Norsk Ergoterapeutforbund. (2017). Alle skal kunne delta. Ergoterapeuters kjernekompetanse. <https://ergoterapeutene.sharepoint.com/Arkiv/7->

Kommunikasjon%20og%20markedsføring/75-

Trykksaker/Kjernekompetanse%202017/Ergoterapeuters\_kjernekompetanse\_Web\_enkeltsider.pdf?ga=1

- Obermeyer, I., Radomski, M. V., Togliola, J., Wolf, T. J., Nadeau, B., Champagne, T., Kuhaneck, H. M., Morrison, M. T., Giles, G. M., & Corcoran, M. A. (2019). Cognition, Cognitive Rehabilitation, and Occupational Performance. *The American Journal of Occupational Therapy*, 73(Supplement\_2), 7312410010p1–7312410010p25. <https://doi.org/10.5014/ajot.2019.73S201>
- Pappadis, M.R., Krishnan, S., Hay, C. C., Jones, B., Sander, A. M., Weller, S. C., & Reistetter, T. A. (2019). Lived experiences of chronic cognitive and mood symptoms among community-dwelling adults following stroke: a mixed-methods analysis. *Aging & Mental Health*, 23(9), 1227–1233. <https://doi.org/10.1080/13607863.2018.1481927>
- Rasquin, Verhey, F. R. J., van Oostenbrugge, R. J., Lousberg, R., & Lodder, J. (2004). Demographic and CT scan features related to cognitive impairment in the first year after stroke. *Journal of Neurology, Neurosurgery and Psychiatry*, 75(11), 1562–1567. <https://doi.org/10.1136/jnnp.2003.024190>
- Regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK). (u.y). *Om å søke REK*. Retrieved 10th May 2023 from [https://rekportalen.no/#hjem/søke\\_REK](https://rekportalen.no/#hjem/søke_REK)
- Smith, J.A., Flowers, P. & Larkin, M. (2012). *Interpretative Phenomenological Analysis. Theory, Method and Research*. SAGE Publications.
- Stigen, L., Bjørk, E., & Lund, A. (2019). The conflicted practice: Municipal occupational therapists' experiences with assessment of clients with cognitive impairments. *Scandinavian Journal of Occupational Therapy*, 26(4), 261–272. <https://doi.org/10.1080/11038128.2018.1445778>
- Stigen, L., Bjørk, E., & Lund, A. (2022). *Occupational Therapy Interventions for Persons with Cognitive Impairments Living in the Community*. <https://doi.org/https://doi.org/10.1080/07380577.2022.2056777>
- Stigen, L., Bjørk, E., & Lund, A. (2023). The power of observation. Occupational therapists' descriptions of doing observations of people with cognitive impairments in the context of community practice. *Scandinavian Journal of Occupational Therapy*, 30(1), 21–33. <https://doi.org/10.1080/11038128.2020.1839966>
- Sun, J.-H., Tan, L., & Yu, J.-T. (2014). Post-stroke cognitive impairment: epidemiology, mechanisms and management. *Annals of Translational Medicine*, 2(8), 80–80. <https://doi.org/10.3978/j.issn.2305-5839.2014.08.05>

- United Nations (UN). (2017). *World Population Ageing 2017 – Report*.  
[https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017\\_Report.pdf](https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Report.pdf)
- United Nations (UN). (2019). *World Population Aging 2019 – Highlights*.  
<https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf>
- Wilcock, A. (1993). A theory of the human need for occupation. *Journal of Occupational Science*, 1 (1), 17-24. DOI: 10.1080/14427591.1993.9686375
- Wilcock, A. A., & Hocking, C. (2015). *An occupational perspective of health* (3rd ed.). Slack Incorporated.
- World Health Organization (WHO). (2002). *Active ageing: a policy framework*. <https://apps.who.int/iris/handle/10665/67215>
- World Health Organization (WHO). (2022, 1. October). *Ageing and health*.  
<https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>

## **Appendix 1: Interview guide**

### **Intervjuguide**

Semi-strukturert intervju. Intervjuguiden vil være ledende under intervjuet.

Oppfølgingsspørsmål knyttet til tema vil bli stilt kontinuerlig. Hovedspørsmål er markert med tall (1,2,3). Mulige oppfølgingsspørsmål eller tema er markert med bokstaver (a,b,c).

### **Introduksjon**

- Takk for at du deltar i prosjektet.
- Mål og hensikt med intervju og prosjektet. Du har samtykket til å være med på et forskningsprosjekt sammen med ergoterapeuten som jobber på rehabiliteringsenheten hvor du har vært. Hensikten med dette intervjuet er å lære fra dine erfaringer knyttet til dette prosjektet.
- Informere om intervjusituasjonen/spørsmål/oppfølgingsspørsmål
- Samtale om personvern.
- Informere om at det vil bli gjort lydopptak av intervjuet og vil bli gjengitt i masteroppgaven.
- Informere om at deltakeren kan trekke seg når som helst under intervjuet uten å oppgi årsak.
- I dette intervjuet er vi opptatt av å høre om dine erfaringer med ergoterapeutens arbeid, men vi vil også vite litt om dine erfaringer med rehabiliteringen som en helhet.

### **Innledende spørsmål**

1. Kan du fortelle litt om deg selv og hvilken skade/sykdom du har gjennomgått?
2. Kan du fortelle litt om hvordan du har opplevd å gjennomgå en slik skade/sykdom og hvilken innvirkning det har hatt?

### **Hoveddel**

3. Hvilke kognitive funksjonsnedsettelse har du og hvordan påvirker de hverdagen din?
  - a. Aktiviteter – jobb, skole, hjem, fritid
  - b. Relasjoner – familie, venner, kollegaer
  - c. Roller – ektefelle, forelder, datter/sønn, barn, venn etc.
4. Hadde du noen mål eller forventninger til rehabiliteringen?



- a. Hvilke yrkesgrupper arbeidet du med for å nå målet ditt?
5. Hva har du gjort sammen med ergoterapeuten?
  - a. Hvem er ergoterapeuten? Vet du hva en ergoterapeut er?
  - b. Kan du fortelle litt om din opplevelse med å bli kartlagt/observert av ergoterapeuten i utførelse av for eksempel morgenstell (aktiviteten(e) som ble valgt)?
  - c. Valg av aktivitet – brukermedvirkning. Opplever du at dere har arbeidet med de «riktige» aktivitetene for deg?
  - d. Å bli observert i aktivitetsutførelse – skummelt, ubehagelig, uvant, helt greit?
  - e. Forståelse av hva som blir kartlagt og observasjonenes betydning.
6. Kan du fortelle litt om dine erfaringer med å jobbe med ergoterapeuten?
  - a. Positive eller negative erfaringer.
  - b. Effekt – bedre eller dårligere sammenlignet med annen ergoterapeutisk intervensjon og tiltak (Eks. På Solås)
7. Har hverdagen forandret seg etter at du har jobbet med ergoterapeuten/deltakelsen i PRPP? Hva tror du er årsaken til dette?
  - a. Positive, negative, store eller små endringer?
  - b. Ingen endring – hvorfor?
8. Hva synes du har vært mest nyttig å jobbe med under rehabiliteringen?
  - a. Er det noe du skullet jobbet mer med under rehabiliteringen?

### **Avsluttende spørsmål**

9. Har du noen råd til personer som nylig har fått kognitive funksjonsnedsettelse?
10. Har du noen råd til ergoterapeutene som skal fortsette å benytte denne metoden eller jobbe med liknende problemstillinger som du har?

### **Avslutning**

- Ønsker du å fortelle om noe vi ikke har snakket om?
- Har du noen spørsmål knyttet til intervjuet, analysering eller prosjektet?

## **Appendix 2: Information letter**

### **Forespørsel om deltakelse i forskningsprosjektet «Personers erfaringer med å leve med kognitive funksjonsnedsettelse og deltakelse i PRPP kartlegging og intervensjon»**

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke personers opplevelse av å leve med kognitive funksjonsnedsettelse og deltakelse i PRPP (Perceive, Recall, Plan and Perform) kartlegging og tiltak. Du er valgt ut basert på informasjon om at du har deltatt i prosjektet «Ergoterapeutisk kartlegging og intervensjon i kommunehelsetjenesten», med informasjon om at du har hatt et hjerneslag eller annen type hjerneskade. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

#### **Formål**

Hensikten med prosjektet er å undersøke personers opplevelse av å leve med kognitive funksjonsnedsettelse etter gjennomgått skade/sykdom. Prosjektet vil videre ha fokus på opplevelsen av å delta i PRPP, som er en ergoterapeutisk metode for kartlegging og tiltak.

#### **Hva innebærer det for deg å delta?**

- Som deltaker i prosjektet vil du bli intervjuet om dine opplevelser om å leve med kognitive funksjonsnedsettelse og deltakelse i PRPP kartlegging og tiltak.
- Det vil bli tatt lydopptak av intervjuet med deg og svarene din vil senere bli benyttet i en masteroppgave, ulike faglige presentasjoner og publikasjoner.
- Prosjektet vil innhente generelle opplysninger om deg som alder, sivilstatus, utdanning, arbeid, diagnose(r) og tid siden skade/sykdom. Opplysningene innhentes direkte fra deg eller din ergoterapeut. Alle opplysninger vil anonymiseres slik at du ikke vil kunne gjenkjennes i presentasjoner eller publikasjoner.

#### **Mulige fordeler og ulemper**

Fordelen med å delta i dette prosjektet er at du kan bidra med kunnskap og innsikt om hvordan det oppleves å gjennomgå skade/sykdom og hvilken påvirkning det kan ha. I tillegg

vil dine opplevelser med å delta i prosjektet du har vært en del av være til stor nytte for å utvikle bruk og gjennomføring av ergoterapeutiske tiltak i kommunehelsetjenesten. For deg som deltaker kan det oppleves utfordrende eller sårbart å dele personlige erfaringer knyttet til din sykdom/skade, dette kan derfor være en ulempe ved å delta.

### **Det er frivillig å delta**

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

### **Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**

- Opplysningene som registreres om deg skal kun brukes som beskrevet i hensikten med prosjektet, og planlegges brukt til 2027. Eventuelle utvidelser i bruk og oppbevaring kan kun skje etter godkjenning fra REK og andre relevante myndigheter.
- Vi behandler opplysningene konfidensielt og i samsvar med personregelverket.
- Dine opplysninger vil bli behandlet uten navn og fødselsnummer, eller andre gjenkjennende opplysninger.
- Kun en kode knytter deg til dine opplysninger.
- Kun prosjektleder Linda Stigen og Malin Rangø Andersen vil ha tilgang til innhentede opplysninger og kodenøkkelen.
- Kodenøkkel, som kobler opplysningene om deg til dataene, 5 år etter prosjektslutt (2027).

### **Dine rettigheter**

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

### **Hva gir oss rett til å behandle personopplysninger om deg?**

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra NTNU – Norges teknisk naturvitenskaplige universitet har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert har vurdert prosjektet og gitt forhåndsgodkjenning. REK nummer: 215391.

### **Kontaktopplysninger**

Hvis du har spørsmål om prosjektet, eller ønsker å benytte deg av dine rettigheter, kan du ta kontakt med:

- Prosjektansvarlig ved NTNU Gjøvik: Linda Stigen, 932 23 019, [linda.stigen@ntnu.no](mailto:linda.stigen@ntnu.no)
- Masterstudent ved NTNU Trondheim: Malin Rangø Andersen, 952 69 155, [malinran@ntnu.no](mailto:malinran@ntnu.no)
- Personvernombud ved NTNU: Thomas Helgesen, [thomas.helgesen@ntnu.no](mailto:thomas.helgesen@ntnu.no)

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på epost ([personverntjenester@nsd.no](mailto:personverntjenester@nsd.no)) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Linda Stigen  
Prosjektansvarlig

Malin Rangø Andersen  
Masterstudent

## Appendix 3: Consent form

### Samtykkeerklæring

**Jeg samtykker til å delta i prosjektet og til at mine personopplysninger brukes slik det er beskrevet prosjektets informasjonsskriv.**

Ja	Nei	
<input type="checkbox"/>	<input type="checkbox"/>	Jeg samtykker til å delta i prosjektet.
<input type="checkbox"/>	<input type="checkbox"/>	Jeg samtykker til lydopptak av intervjuet.

\_\_\_\_\_  
Sted og dato

\_\_\_\_\_  
Deltakers signatur

\_\_\_\_\_  
Deltakers navn med trykte bokstaver

Stedfortredende samtykke. Som nærmeste pårørende til \_\_\_\_\_  
(Fullt navn) samtykker jeg til at han/hun kan delta i prosjektet.

\_\_\_\_\_  
Sted og dato

\_\_\_\_\_  
Pårørendes signatur

\_\_\_\_\_  
Pårørendes signatur med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet:

\_\_\_\_\_  
Sted og dato

\_\_\_\_\_  
Signatur

\_\_\_\_\_  
Rolle i prosjektet



 **NTNU**

Norwegian University of  
Science and Technology