

# «Giving people a chance»

## – HOW PEOPLE WITH TRAUMATIC BRAIN INJURY EXPERIENCE WORK PARTICIPATION TEN TO TWELVE YEARS AFTER THE INJURY

Av Øyvor Haugsbakk Talåsen, Nada Andelic & Unni Sveen

### Abstract

**Purpose:** The study aimed to explore how people with moderate-to-severe traumatic brain injury (TBI) experienced work participation ten to twelve years after their injury. The goal was to contribute to the knowledge base on how to best improve work participation for this group.

**Methods:** Data were collected through semi-structured interviews with eight individuals from eastern Norway who had experienced moderate-to-severe TBI ten to twelve years earlier. The data were analysed using a stepwise-deductive inductive method.

**Findings:** The informants' experiences with work participation can be described in two main themes:

- 1 working with impaired memory, attention and fatigue
- 2 the importance of coping strategies and social support in returning to work

The informants described work participation as positive; however, they reported challenges with «invisible» consequences such as fatigue, reduced attention and impaired memory. Coping strategies were applied to compensate for these impairments. The informants also reported challenges resulting from the limited understanding of colleagues of their injury-related issues.

**Conclusions:** The informants still experienced challenges in the workplace ten to twelve years post injury. The findings indicate that TBI follow-up programmes should include interventions such as workplace-based support and work adaptations with a long-term perspective.

**Keywords:** Biopsychosocial model, long-term consequences, occupational science, traumatic brain injury, qualitative method.



*Øyvor Haugsbakk Talåsen er ergoterapeut og seniorrådgiver ved Statped, avdeling for ervervet hjerneskade.*



*Nada Andelic er professor ved avdeling for folkehelsevitenskap ved Universitetet i Oslo og overlege ved avdeling for fysikalsk medisin og rehabilitering, Oslo universitetssykehus.*



*Unni Sveen er professor emerita ved Oslo Met og Avdeling for fysikalsk medisin og rehabilitering ved Oslo Universitetssykehus.*

*Manuset ble mottatt 20.11.2022, og det ble godkjent for publisering 08.05.2023. Det er ingen interessekonflikter.*

## Introduction

A substantial number of people with traumatic brain injury (TBI) experience physical, cognitive, behavioural and emotional changes, as well as reduced social function and work participation (1-7). A systematic review and meta-analysis found that only 35 percentage of individuals with moderate or severe TBI had returned to work by their one-year follow-up, increasing to 50 percentage at five years and beyond. However, only one-third of individuals returned to their pre-injury work levels (8). Ponsford et al. (4) showed that a large proportion of TBI-affected individuals worked part-time ten years after their injury, suggesting the existence of long-lasting challenges related to work participation.

The socioeconomic consequences of TBI are considerable, as are the consequences for those suffering TBI (8,11). Several studies have investigated factors that may promote work participation following TBI and have found that education level, pre-injury employment status, age at time of injury and the development of coping strategies are important aspects (12-16). Previous research has identified several challenges in work participation following TBI. Fatigue, which impacts attention and other cognitive functions, can lead to poor work quality (2,6,17) and cognitive difficulties, such as impaired memory and difficulty in learning new tasks, can also become a barrier to work participation. This is consistent with a systematic review that emphasises the importance of cognition for work participation (2). A study by Esbjörnson et al. (18) assessing the impact of impaired executive function on work performance, showed that TBIs can reduce the ability to plan, make decisions and meet deadlines. In addition, the impact of these cognitive challenges is often «invisible» and difficult for others to understand (19).

Little evidence exists regarding the relationship between specific workplace factors and work participation among people with TBI (20). The existing information emphasises a lack of knowledge and understanding of the consequences of the injury on the part of colleagues and workplace leaders', which may present a challenge for work participation (6,21,22). One study reported that creating a good dialogue and flexible working practices increased the probability of coping at work (19). Another challenge reported is that, over time, employers and colleagues may gradually increase their expectations and no longer have the same tolerance for the

injured person's reduced capacity (6). People with TBI may also experience stigmatisation, for example, because they can no longer carry out their previous duties (23,24). It can be difficult to accept that life has changed and adjust to the new reality by finding a balance in a new life situation (25,26).

Bush et al. (13), in their qualitative study of experiences two to ten years after TBI, suggested that people who had paid work or volunteered to work after TBI experienced a better quality of life than the comparison groups. A failure to return to work has a wider social impact when individuals become permanently dependent on social security benefits (6). Work is the foundation of people's welfare, and it is, therefore, important to have a work environment where there is a place for everyone (29). Work participation creates a sense of belonging and contributing to society while ensuring financial security (26,31). Previous quantitative studies of individuals with TBI five to ten years after injury conclude that increased attention is needed on the long-term consequences of these injuries (3,33,34).

Overall, the existing literature shows that people with TBI experience multiple challenges in their working lives and work participation. However, few qualitative studies described how people with TBI experience work participation as late as ten to twelve years after their injury. We need greater knowledge about work participation after TBI to gain insight into how we can facilitate participation. An insight into how people experience work participation ten to twelve years post-injury, will help us understand how we can ensure that people stay at work, despite the challenges. This is one of the first qualitative long-term follow-up studies from a Scandinavian welfare state characterised by high job security, low unemployment, and a comprehensive welfare system, but limited demand for low-productivity labour. These contextual factors may reduce the potential for work-support interventions to increase work participation after TBI (35). The study aims, therefore, to explore how people with moderate-to-severe TBI experience work participation ten to twelve years after their injury. It focuses on how they cope with work tasks and how they believe they are seen by colleagues and managers. Greater information about and knowledge of work participation experiences in the late recovery phase after TBI may be useful from a health care perspective and help clarify the need for long-term vocational rehabilitation and workplace adjustments.

## THEORETICAL PERSPECTIVE

To understand the meaning of work as an occupation, this study used a theoretical perspective from occupational science (28,30). The theory highlights the role of meaningful engagement in an occupation to cope with, and live through, transitions such as TBI (28,30). To the best of our knowledge, few qualitative studies have examined work experiences after TBI in light of this theoretical perspective. In this study, the term «occupation» includes everything we do, take part in, show interest in, and have expectations of (28,30). People develop through occupations, which affect both life and health (25,36). Work participation, as an occupation, contributes to shaping the individual's occupational identity (19, 23, 36). The theory is used to gain insight into the individual's sense of their capacity for and efficiency in work participation after TBI (19,23). TBI occurs abruptly and unexpectedly and thus disrupts an individual's roles and valued activities (28,30). It can affect their occupational identity and change their perception of their own competence (28,30), an important factor in their development of coping strategies in the workplace. Furthermore, TBI requires an increased focus on occupational balance: The balance between the work activities required and the person's resources (37). Work participation provides stability and normality, which underscores the importance of work participation (28,30). Occupational science was used to gain insights into the informant's experiences with occupational identity, including work mastering and coping strategies. Further, the theory was used to understand the environmental understanding of activity balance.

The relationship between TBI and work participation can be understood through George Engel's biopsychosocial model, which illustrates how the interaction between different spheres of working life affects work participation (38,39). The biopsychosocial model is based on a combination of two different frameworks of disability, social and medical. In the biopsychosocial model, TBI and work participation are understood to mutually influence biological, psychological and social factors (38,39). The biological dimension includes somatic disease, which refers in this case to the consequences of the TBI, such as fatigue and reduced memory and concentration. The psychological dimension addresses how self-concept may be challenged after TBI, and the social dimension is concerned with social

support and belonging in the workplace. In this study, the biopsychosocial model was applied in the analysis and discussion to clarify the complexity of work participation after TBI. The purpose was to examine how the various aspects play a role in work participation through gaining insight into the complex interaction between individual resources and the environment. The theoretical perspectives, both one derived from occupational science and Engel's biopsychosocial model, are used to illuminate the complexity and the importance of facilitating work participation after TBI.

## Method

### PARTICIPANTS

The participants were recruited from an ongoing long-term quantitative follow-up study of people with moderate-to-severe TBI living in Eastern Norway, who had been injured from 2005 to 2007. The purpose of the main study was to better understand the mechanisms, course and long-term outcomes of TBI, including employment (15). Purposive sampling was conducted on the list of participants in the main study. The inclusion criteria were that the informants had to have experienced full- or part-time work for at least two of the ten to twelve years after their injury, and that both sexes should be represented. Ten consecutive people who met the inclusion criteria were informed of the purpose of the study and asked to participate. Two declined and eight informants were therefore included. Five were men and three were women, aged between 30 and 52 years (see Table 1). Work participation has been conceptualised in this study by applying an inclusive definition of employment (9,10) which includes other activities such as studying. Students, in this study, refers to those studying at a high school, college or university in order to enter specific professions. Working or studying full-time equates to 37.5 productive hours per week (i.e. 100 percentage); part-time employment was defined as working less than 37.5 hours per week (9,10). Three of the informants were twelve years post-injury, four were eleven and one ten years post injury. Most informants in this study were students at the time of their injury with limited experience of the workplace. However, as students, they were used to learning and acquiring knowledge and therefore, had important and relevant insights into how TBI affected their studying/work capacity. Therefore, students were classified as working, since studying

Name, age	Severity of injury by GCSI <sup>1</sup>	Injury mechanism	Work at time of injury	Work ten to twelve years after the injury	Job percentage ten to twelve years after TBI
Oliver, 38	Moderate	Fall accident	Student	Independent trader	100 %
Jessica, 30	Moderate	Car accident	Student	Health care	50 %
Jack, 52	Moderate	Car accident	Economist	Economist	100 %
Daniel, 49	Moderate	Car accident	Adviser	Adviser	100 %
David, 45	Severe	Car accident	Health care worker	Health care worker	100 %
Ronnie, 32	Severe	Fall accident	Student	Engineer	40 % temporary jobs periodically
Zara, 31	Severe	Car accident	Student	Health and care worker	80-100 %
Emma, 36	Severe	Fall accident	Student	Shop Assistant	50 %

Table 1: Presentation of eight informants, interviewed ten to twelve years after traumatic brain injury.  
Note: <sup>1</sup> GSC, Glasgow Coma Scale.

was regarded as a productive activity (9,10). All the informants were employed and had several years of work experience. Participation was voluntary and based on oral and written consent (41).

#### DATA COLLECTION

A qualitative approach was chosen to capture the informants' descriptions, opinions and experiences. A semi-structured interview was conducted with each participant in October-November 2017. The reporting of the study follows the standards for reporting qualitative research guidelines (SRQR) (42). The first author conducted the interviews, lasting 45-60 minutes, face to face, enabling observation of tone of voice and body language. The interviews were conducted in Norwegian at a location chosen by the informants. They were audio-recorded with the consent of the informants and subsequently transcribed verbatim and translated into English. After the seventh and eighth interviews, the interviewer found that the informants raised similar themes, unsolicited, and offered little new information. Applying a consecutive process of interview transcription and preliminary analysis, it was possible to detect whether new themes were presented by the informants. Thus after the eighth interview, it was determined that saturation was reached, and all co-authors agreed that the eight informants had provided adequate data about work participation after TBI. According to Tjora, saturation is reached when no new information is discovered in the data analysis, signalling to the researchers that data collection may cease (40).

The interviews started with a presentation by the interviewer and a brief recapitulation of information about the study, open-ended questions were then asked about the injury and current work. The intention was to prepare the informants for the interview and to create a free conversation in a relaxed atmosphere where the informant could reflect on their own experiences and opinions of work participation after TBI (40). The interview focused on questions that would prompt the informants to tell stories and talk in detail on the topic of work participation (40). The participants were asked about their experiences of working, potential challenges, coping strategies and social support in the workplace. At the end of the interview, they had the opportunity to elaborate or add to their answers if they wished. The transcribed interviews resulted in 99 pages of data material.

#### ANALYSIS

The first author is an occupational therapist with experience as an active, clinical therapist working with people with TBI. The author met the informants for the first time when conducting the interviews. The analysis was conducted by the first author in collaboration with the third author, a senior occupational therapist. The second author, a professor in physical medicine and rehabilitation, was involved in the final phases of the analysis and interpretation of the data. Excerpts from the transcript were discussed and reviewed for interpretation and thematization. The collected qualitative data were then analysed based on a stepwise-deductive indu-

ctive method (SDI) (40). This approach alternates continually between inductive interpretation and theoretical proximity during analysis (40). The approach starts inductively and subsequently draws on existing theory in concept development. The model aims to create codes generated from data, not from theory, hypotheses, research questions, or previously set themes (40).

The first step of the SDI method describes the generation of empirical data and processing of the raw data. The interviews were uploaded to the computer program NVivo 11 (Version 12, QRS International) and systematically reviewed and coded from the empirical data (40). The codes were made by summarising sections of text with sentences that conveyed what the informants said. The codes were tested to ensure they contained what the informants said, and not what they talked about to ensure empirical coding (40). The coding in SDI is referred to as open or initial coding (40).

In the second step, the codes were grouped according to relevance to the research question and inner thematic meaning. The codes served as detailed labels or keywords (40). The code grouping was inductive in that the codes were moved from NVivo 11 and sorted into word documents by themes and common features. Models and mind maps were drawn to look for related codes. For example, the various coping strategies mentioned were grouped under the same code. The authors conducted this part of the analysis in consultation with each other to validate the code groupings, as well as to evaluate the possibility of data saturation.

In the last step, the text was further analysed and classified into concepts to which theory was applied. This supported the analysis with a framework for understanding the empirical material and exploring new theoretical aspects in the deductive analysis. For example, the coping strategies used by informants were thematised, as were the types of support they believed to be important for work participation. These strategies supported the person's identity, as described within occupational science (28,30). This concept development gives the study a more generic value and improves its generalisability (40). The code groups were categorized by the overarching themes that formed the concepts and then checked against the empirical data. Occupational science was applied to gain insight into how the informants described the different factors that influenced their work participation (28,30). The bio-

psychosocial model formed the themes by showing the complexity of work participation after TBI. The individuals' coping strategies alone were not sufficient to master work participation; they needed support from other dimensions in the model. Two main themes were developed during the analysis. The first describes how the informants express working with challenges related to TBI, and the second identifies the importance of coping strategies and social support in mastering work participation.

## ETHICS

The study adhered to the research ethics guidelines for the social sciences prepared by the National Research Ethics Committee. Before conducting the interviews, this project obtained approval from the Regional Committees for Medical and Health Research Ethics (REC nr. 2015/1589). REC approved the change notification that was submitted to conduct the interviews with selected informants. The informants were guaranteed confidentiality. To this end, any personal information that could reveal their identity has been omitted from the interview transcripts (41).

## Findings

The informants' experiences of work participation ten to twelve years after moderate-to-severe TBI were interpreted under two main themes, identified in the structural analysis:

- 1 *working with impaired memory, attention, and fatigue*
- 2 *the importance of coping strategies and social support in returning to work*

## WORKING WITH IMPAIRED MEMORY, ATTENTION AND FATIGUE

The informants talked about the challenges they faced in the workplace and described difficulties with impaired memory, attention and fatigue. Jack experienced life with fatigue and a constant lack of interest in anything. Emma described how the workday affected her: «*I keep working, but then I break down when I get home. I have taught myself to live with it, but I'm afraid one day I will break down totally.*»

The informants talked about challenges that led to significant uncertainty and made it very difficult to participate in work. Ronnie described how he needed reminders to complete tasks. Zara, who held a position in health care services, described challen-



ges caused by impaired attention and memory when attending a team meeting: *«I may not have noticed and remembered the name of one of our clients – then you sit and feel very uncertain. If I get a question about this client now, addressed to me, then I do not know what to say, and that is an issue.»*

Several of the informants were concerned about whether the difficulties they experienced at the workplace were related to their injury or due to other factors. Oliver described how he became tired during the working day, but thought it was difficult to know whether this was due to the injury or whether he would have become tired anyway as part of everyday life. Some of the informants were young, with little or no work experience when the injury occurred. With no comparison, it was difficult for them to know what caused the challenges they faced at work. Oliver described it in this way:

*«Sometimes it is difficult to know whether I'm tired because of ordinary activities in my everyday life or because of the brain injury – or is it both? Do I get tired now because I have no exercise and only work – the time squeeze and all that? There are so many other things at play here.»*

### **THE IMPORTANCE OF COPING STRATEGIES AND SOCIAL SUPPORT IN RETURNING TO WORK**

The informants talked about their experience of working after TBI, and how they had adapted to their work situations by developing a variety of coping strategies. Daniel had found using e-mail more helpful than making phone calls as the conversation was then stored, serving as an aid for his impaired memory. *«Now I can document what we have talked about. It works as a protection, as well as an aid.»*

Jessica chose to reduce the number of days she worked each week, which alleviated her symptoms and made her more efficient at work. *«So, all the symptoms I get when I'm tired, such as poor memory and poor sleep. Yes, you know, all these challenges. They are exactly the challenges I now avoid, working fewer days per week.»*

Other coping strategies the informants described included taking breaks, taking advantage of flexible working hours, and using compensatory aids such as calendars, checklists, and retreating. These measures allowed them to work at their own pace without time pressure and gave them the opportunity to manage their work participation with reduced capacity. Furthermore, openness, understanding and good communication with their employers and colleagues

were described as important factors. David explained that being part of something was a sufficient motivation for him to stay employed.

The informants talked about the various challenges they faced at work. For several of the informants, «invisible challenges», such as reduced mental capacity and impaired attention, were barriers to working life. They explained that it was difficult for others to understand: Daniel's co-workers had quickly begun to demand greater productivity than he could deliver, and Emma's colleagues showed little understanding of the consequences of her injury – she felt she would have been more easily understood if she were in a wheelchair. Daniel described the «invisible challenges» as follows: *«Say somebody at work breaks their right arm – you don't work as efficiently with the left arm – and people don't automatically require you to be efficient, because they can see the problem, right.»*

David also related that he had heard from another person with a TBI that the threshold for work participation in general had become too high. He commented that an increasing number of workplaces require trade certificates that make it difficult for people with brain injuries to work. He believed that in the Scandinavian labour context, demand is increasing for high productivity and efficiency, and there is limited demand for low productivity labour. Ronnie's experience with this system was described as «drowning». Daniel also described it as an obstacle to work participation after TBI: he missed part-time working that does not stigmatise the individual. *«It is about giving people a chance and not placing them at the end of the queue – don't kill the motivation. Not sheltered work, because that only stigmatises or hurts people, I think.»*

Another challenge was that managers did not understand the consequences of brain damage, and the informants often lacked social support from colleagues. Several of the informants had chosen not to inform their employers about their challenges because of previous negative experiences in doing so. Emma's supervisor trivialised her problems, and she did not feel understood. Other informants talked about good relationships with their colleagues and described how important these were to them. Jack wanted the workplace to know about his issues, but did not want it to create obstacles to participation: *«I want people to be aware that I have actually been injured – it's not just a scratch, but I don't want to be treated differently.»*

At the same time, some participants had found that their colleagues did not consider the challenges they faced. Emma had informed her colleagues about her accident but felt that they did not see her as reliable because of her cognitive challenges. She felt inferior and undervalued by her colleagues.

*«Actually, you have finished your education and expect to be seen as a professional with the qualities that entails – but, because of the way you talk – and maybe walk – everyone forms their own opinion and interprets it in their own way; therefore, they sometimes underestimate you.»*

## Discussion

The main findings of this qualitative study are that the consequences of moderate-to-severe TBI continue to influence work participation ten to twelve years post-injury, and that those affected develop coping strategies to compensate for impaired functioning. The findings are based on long-term work participation in a Scandinavian welfare state context (35) and are interpreted in a biopsychosocial (38,39) and occupational science (28,30) theoretical framework.

The findings illustrate the relationship between specific workplace factors and work participation among people with TBI (20). The biopsychosocial model is applied in the discussion to explore the complexity of work participation (38,39).

### ACCEPTING THEIR NEW SITUATION

The informants described difficulties with reduced memory and impaired attention and saw these as a barrier to work participation, in line with previous studies (2,6,22,43). The biological changes caused by brain injury may lead a person to redefine their occupational identity, as the informants in this study described. They had to accept their new situation and find strategies to compensate for their reduced cognitive function. These findings correspond to key ideas in occupational science (28,30). TBI has affected their occupational identity and, therefore, changed their perception of their competence through accepting their new occupational identity and coping strategies (28,30). These challenges can affect self-image and identity. Conversely, an individual's ability to redefine their identity can have a positive effect on the biological aspects and make it easier for them to tolerate changes. This ability increases the likelihood of promoting a positive self-image (19,23). At the same time, the findings showed that

the social dimension could also be decisive for work participation.

### THE IMPORTANCE OF SOCIAL SUPPORT

The informants describe various experiences of a lack of understanding on the part of management and colleagues. Ellingsen (6) relates this to insufficient knowledge about the injury, in line with Bonnetterre et al. (44), who indicate the importance of social support in the workplace. However, the findings show that several of the informants had chosen not to inform their workplace about the challenges they face, which may have created a barrier to their own work participation. At the same time, this may have been a conscious choice because the individuals did not want to violate their occupational identity. In light of the biopsychosocial model, this shows how the social dimension affected and was influenced by the psychological and biological factors, even ten to twelve years after the injury (38,39).

### THE «INVISIBLE» CONSEQUENCES

The informants talked about challenges associated with the «invisible» consequences of TBI, in line with Sveen et al. (19) who found that «invisible» symptoms were perceived as a burden. As time passes, it can be difficult for colleagues to remember the challenges the individual faces, and they therefore begin to expect more from them (36). Emma had to emphasise the «invisible» consequences in order to be understood, and felt that she would have been better understood had she been in a wheelchair. Such experiences may be related to insufficient knowledge in society. Biological changes, combined with reduced understanding or knowledge in the social context, can refer to how previous studies discuss stigmatized identity (24,45). This corresponds to Emma's description of being underestimated in the workplace. However, experience of a stigmatised identity can also occur in the psychological dimension, showing the causality in the biopsychosocial model (38,39). According to Bryson-Campbell et al. (23), experience of stigmatised identity is an obstacle to work participation. From an occupational science perspective, this can concern violations of the individual's occupational identity. At the same time, novel findings in this study show that the informants found it difficult to know whether the challenges they were currently experiencing in the workplace were injury-related or would have existed without the injury.

## COPING STRATEGIES

Another distinct finding of this study lies in the descriptions of the various coping strategies the informants developed to make work participation easier, such as using checklists and calendars. Coping strategies that break down tasks into manageable chunks are important, as shown in previous studies (14,32), underlining the causality of the biopsychosocial model (38,39). Biological and social factors affect the psychological dimension and vice versa. An individual's sense of their own capacity is developed and reinforced through interactions with other people, which relates to the theory of occupational science (19,23).

## THE PROLONGED PROCESS

The findings of this study show that the prolonged process of coping with multiple challenges in order to succeed in work participation after a TBI requires patience and understanding. The informants experienced challenges due to the disruption of their occupational identity, and several had spent many years redefining their self-understanding, in line with results from previous studies (19,23). Due to their reduced work capacity, it was important for the participants to start in a reduced position and increase gradually. They became more tired than before their injury, and they focused on strengthening the balance between activity and rest. The need for an increased focus on occupational balance was described by Jessica, who reduced her working hours to achieve it. Workplaces must, therefore, offer more flexibility by adapting work tasks or working hours to give the employee the opportunity to adapt to the new requirements that may arise after a TBI and thus achieve occupational balance (6,37).

The findings confirm the challenges of work participation. David, therefore, called for a system that gives people a chance to stay employed, and this would also help people to move on with their lives post-TBI. Society has created a barrier to work participation in that some workplaces require trade certificates, making it difficult for people with brain injuries to work if they are not in a position to acquire such certificates.

The findings also showed that the term «sheltered work» can be seen as stigmatising. This suggests the informants' desire not to stand out, linked to Bryson-Campbell's (23) description of stigmatised identity. Both the biological dimension (i.e. the consequences of TBI) and the social dimension (i.e.

a lack of understanding by others) can thus have a negative impact on the psychological dimension. This corresponds to the findings of Libeson et al. (46) who showed how individuals experience work satisfaction and that their quality of life depends on work participation. From an occupational science perspective, this demonstrates that work participation is essential in shaping the individual's occupational identity (19,23,36).

## Methodological considerations

According to Tjora (40), the SDI method for data analysis applied in this study, supports reliability by establishing detailed requirements for data generation, empirical analysis and application of the relevant theory in the final phase. The study used a sample of eight informants, selected according to the purpose of the study. Their characteristics were appropriate to enable them to contribute to a detailed exploration and understanding of the topic (41). It should be emphasised that the findings clarified the perspectives only of individuals who had experienced a TBI. Important information from the social environment surrounding those individuals was not gathered. It may therefore be relevant in future studies to examine this topic from multiple perspectives and apply other theoretical approaches. While the sample size was small, all the participants were representative of people with moderate-to-severe TBI, and they provided rich data about their own experiences. The findings make a new contribution to the knowledge base regarding work participation following TBI and potential areas of improvement in the workplace.

## Conclusions

This study provides insight into how the consequences of TBI affect work participation ten to twelve years post-injury. The findings show that even at this late stage it can be difficult to find a balance in everyday life. Reduced memory, impaired attention and a lack of understanding on the part of management and colleagues created challenges in work participation. Individuals develop coping strategies for work participation, as described by the participants, but there is a need for improved working practices based on enhanced understanding, knowledge, and social support in the late phases of TBI recovery. In addition, we need a greater knowledge of which factors affect work participation from a long-term perspective, an area to which occupational therapists can contribute with their expertise in vocati-



onal rehabilitation. The findings give occupational therapists insight into how work participation can be facilitated at both systemic and individual levels. Adaptations such as tailoring work tasks and adjusting working hours, can promote activity balance and quality of life after TBI. The findings contribute to the knowledge base on work participation following TBI and potential areas of improvement in the workplace, potentially widening access to work participation. Further research and dialogue will improve our understanding of the central challenges in promoting workplace adaptations and work participation after TBI.

## Funding

The study was partly financed by Oslo University Hospital.

## Acknowledgements

We would like to thank the informants for sharing their experiences with us.

## References

- Matérne M, Lundqvist LO, Strandberg T. Opportunities and barriers for successful return to work after acquired brain injury: A patient perspective. *Work*. 2017;56(1):125-34.
- Mani K, Cater B, Hudlikar A. Cognition and return to work after mild/moderate traumatic brain injury: A systematic review. *WORK*. 2017;58(1):51-62.
- Andelic N, Soberg HL, Berntsen S, Sigurdardottir S, Roe C. Self-perceived health care needs and delivery of health care services 5 years after moderate-to-severe traumatic brain injury. *Pm r*. 2014;6(11):1013-21; quiz 21.
- Ponsford JL, Downing MG, Olver J, Ponsford M, Acher R, Carty M, et al. Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. *J Neurotrauma*. 2014;31(1):64-77.
- Ketchum JM, Almaz Getachew M, Krch D, Kolkowsky-Hayner SA, Baños JH, Lequerica A, et al. Characteristics associated with satisfaction with life 1 year post traumatic brain injury in a population of Hispanic individuals. *NeuroRehabilitation*. 2012;30(1):23-33.
- Ellingsen KL AR. Work participation after acquired brain injury: experiences of inhibiting and facilitating factors. *Int J Disabil Manage Res*. 2009;4(1):1-11.
- Sigurdardottir S, Andelic N, Wehling E, Anke A, Skandsen T, Holthe OO, et al. Return to work after severe traumatic brain injury: a national study with a one-year follow-up of neurocognitive and behavioural outcomes. *Neuropsychol Rehabil*. 2020;30(2):281-97.
- Andelic N, Stevens LF, Sigurdardottir S, Arango-Lasprilla JC, Roe C. Associations between disability and employment 1 year after traumatic brain injury in a working age population. *Brain Inj* 2012;26(3):261-269.
- Forslund MV, Roe C, Arango-Lasprilla JC, Sigurdardottir S, Andelic N. Impact of personal and environmental factors on employment outcome two years after moderate-to-severe traumatic brain injury. *J Rehabil Med*. 2013;45(8):801-7.
- Gormley M, Devanaboyina M, Andelic N, Røe C, Seel RT, Lu J. Long-term employment outcomes following moderate to severe traumatic brain injury: a systematic review and meta-analysis. *Brain Inj*. 2019;33(13-14):1567-80.
- Maas AIR, Menon DK, Adelson PD, Andelic N, Bell MJ, Belli A, et al. Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *Lancet Neurol*. 2017;16(12):987-1048.
- Franulic A, Carbonell CG, Pinto P, Sepulveda I. Psychosocial adjustment and employment outcome 2, 5 and 10 years after TBI. *Brain Inj*. 2004;18(2):119-29.
- Dahm J, Ponsford J. Predictors of global functioning and employment 10 years following traumatic brain injury compared with orthopaedic injury. *Brain Inj*. 2015;29(13-14):1539-46.
- Bush EJ, Hux K, Guetterman TC, McKelvey M. The diverse vocational experiences of five individuals returning to work after severe brain injury: A qualitative inquiry. *Brain Inj*. 2016;30(4):422-36.
- Howe EI, Andelic N, Perrin PB, Røe C, Sigurdardottir S, Arango-Lasprilla JC, et al. Employment Probability Trajectories Up To 10 Years After Moderate-To-Severe Traumatic Brain Injury. *Front Neurol*. 2018;9:1051.
- Jacobs, K. Work and traumatic brain injury. *WORK*. 2017;58(1):1-2.
- Jonasson A, Levin C, Renfors M, Strandberg S, Johansson B. Mental fatigue and impaired cognitive function after an acquired brain injury. *Brain Behav*. 2018;8(8):01056.
- Esbjörnsson E, Skoglund T, Sunnerhagen KS. Fatigue, psychosocial adaptation and quality of life one year after traumatic brain injury and suspected traumatic axonal injury; evaluations of patients and relatives: a pilot study. *J Rehabil Med*. 2013;45(8):771-7.
- Sveen U, Søberg HL, Østensjø S. Biographical disruption, adjustment and reconstruction of everyday occupations and work participation after mild traumatic brain injury. A focus group study. *Disabil Rehabil*. 2016;38(23):2296-304.
- Alves DE, Nilsen W, Fure SCR, Enehaug H, Howe EI, Løvstad M, et al. What characterises work and workplaces that retain their employees following acquired brain injury? Systematic review. *Occup Environ Med*. 2020;77(2):122-30.
- Björkdahl A. The return to work after a neuropsychological programme and prognostic factors for success. *Brain Inj*. 2010;24(9):1061-9.
- Gilworth G, Eyres S, Carey A, Bhakta BB, Tennant A. Working with a brain injury: personal experiences of

- returning to work following a mild or moderate brain injury. *J Rehabil Med.* 2008;40(5):334-9.
23. Bryson-Campbell M, Shaw L, O'Brien J, Holmes J, Magalhaes L. A scoping review on occupational and self identity after a brain injury. *Work.* 2013;44(1):57-67.
  24. Soeker MS, Darris Z. The experiences of women with traumatic brain injury about the barriers and facilitators experienced after vocational rehabilitation in the Western Cape Metropole, South Africa. *WORK.* 2019;64(3):447-486.
  25. Rubenson C, Svensson E, Linddahl I, Björklund A. Experiences of returning to work after acquired brain injury. *Scand J Occup Ther.* 2007;14(4):205-14.
  26. Lundqvist A, Samuelsson K. Return to work after acquired brain injury: a patient perspective. *Brain Inj.* 2012;26(13-14):1574-85.
  27. Shames J, Treger I, Ring H, Giaquinto S. Return to work following traumatic brain injury: trends and challenges. *Disabil Rehabil.* 2007;29(17):1387-95.
  28. Kristensen, Hanne Kaae. Occupational science in a Nordic environment. *Journal of occupational science*, 2019, Vol.26 (2), p.193-199.
  29. Stortingsmelding 29. Felles ansvar for eit godt og anstendig arbeidsliv: Arbeidsforhold, arbeidsmiljø og sikkerhet. Det Kongelige Arbeidsdepartement. Oslo 2010-2011.
  30. Yerxa, E. J., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D., Stein, C., & Zemke, R. (1989). An introduction to occupational science: A foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*, 6, 1-17.
  31. Saltychev M, Eskola M, Tenovuori O, Laimi K. Return to work after traumatic brain injury: Systematic review. *Brain Inj.* 2013;27(13-14):1516-27.
  32. Gilworth G, Carey A, Eyres S, Sloan J, Rainford B, Bodenham D, et al. Screening for job loss: development of a work instability scale for traumatic brain injury. *Brain Inj.* 2006;20(8):835-43.
  33. Pösl M, Cieza A, Stucki G. Psychometric properties of the WHODASII in rehabilitation patients. *Qual Life Res.* 2007;16(9):1521-31.
  34. Draper K, Ponsford J. Cognitive functioning ten years following traumatic brain injury and rehabilitation. *Neuropsychology.* 2008;22(5):618-25.
  35. Reme SE, Monstad K, Fyhn T, Sveinsdottir V, Løvvik C, Lie SA, Øverland S. A randomized controlled multicenter trial of individual placement and support for patients with moderate-to-severe mental illness. *Scand J Work Environ Health* 2019;45(1):33-41.
  36. Gallagher M, Muldoon OT, Pettigrew J. An integrative review of social and occupational factors influencing health and wellbeing. *Front Psychol.* 2015;6:1281.
  37. Eklund M, Orban K, Argentzell E, Bejerholm U, Tjörnstrand C, Erlandsson LK, et al. The linkage between patterns of daily occupations and occupational balance: Applications within occupational science and occupational therapy practice. *Scand J Occup Ther.* 2017;24(1):41-56.
  38. Engel GL. The need for a new medical model: a challenge for biomedicine. *Psychodyn Psychiatry.* 1977;196(4286):129-136.
  39. Xiao X, Song H, Sang T, Wu Z, Wie Y, Yang Q. Analysis of Real-World Implementation of the Biopsychosocial Approach to Healthcare: Evidence From A Combination of Qualitative and Quantitative Methods. *Front Psychiatry.* 2021;12. doi: <https://doi.org/10.3389/fpsy.2021.725596>
  40. Tjora A. *Qualitative research as stepwise-deductive induction.* 1st ed: Taylor & Francis Ltd.; 2018.
  41. Kvale S; Brinkmann S. *InterViews: Learning the craft of Qualitative Research interviewing.* Los Angeles: Sage Publications; 2009.
  42. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.
  43. Harrison AL, Hunter EG, Thomas H, Bordy P, Stokes E, Kitzman P. Living with traumatic brain injury in a rural setting: supports and barriers across the continuum of care. *Disabil Rehabil.* 2017;39(20):2071-80.
  44. Bonnetterre V, Pérennou D, Trovatiello V, Mignot N, Segal P, Balducci F, et al. Interest of workplace support for returning to work after a traumatic brain injury: a retrospective study. *Ann Phys Rehabil Med.* 2013;56(9-10):652-62.
  45. Johansson U, Tham K. The meaning of work after acquired brain injury. *Am J Occup Ther.* 2006;60(1):60-9.
  46. Libeson L, Downing M, Ross P, Ponsford J. The experience of return to work in individuals with traumatic brain injury (TBI): A qualitative study. *Neuropsychol Rehabil.* 2020;30(3):412-29.