# Biographical disruption, adjustment and reconstruction of everyday occupations and work participation after mild traumatic brain injury. A focus group study.

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#### Abstract

Purpose: To explore traumatic brain injury (TBI) as a biographical disruption and to study the reconstruction of everyday occupations and work participation among individuals with mild TBI.

Methods: Seven focus groups were conducted with 12 women and 8 men (22-60 years) who had sustained mild TBI and participated in a return-to-work programme. Interviews were analysed using qualitative content analysis.

Results: Four interrelated themes emerged: disruption of occupational capacity and balance; changes in self-perceptions; experience of time; and occupational adjustment and reconstruction. The meaning of the impairments lies in their impact on the individual's everyday occupations. The abandonment of meaningful daily occupations and the feeling of not recognising oneself were experienced as threats to the sense of self. Successful integration of the past, present and future was paramount to continuing life activities. The unpredictability of the future seemed to permeate the entire process of adjustment and reconstruction of daily life.

Conclusions: Our findings show that the concept of time is important in understanding and supporting the reconstruction of daily life after TBI. The fundamental work of rehabilitation is to ameliorate the disruptions caused by the injury, restoring a sense of personal narrative and supporting the ability to move forward with life.

## Introduction

Traumatic brain injury (TBI) is a disabling condition that affects several aspects of everyday life, including social and vocational participation [1,2]. People with TBI experience diverse challenges in functioning. Cognitive, emotional, and behavioural problems are often reported regardless of the severity of the injury [3,4]. TBIs are usually classified as mild, moderate or severe based on the Glasgow Coma Scale (GCS) [5]. Mild injury is the most common form of TBI, with an estimated occurrence rate of 70-80%.

Following mild TBI, typical impairments include cognitive symptoms, such as reduced concentration and memory, and a lack of energy [6,7]. So far, most quantitative and qualitative studies [8] have focused on individual issues, such as impaired executive function [9,10], problems with motivation [11], stress [12,13], fatigue and sleep disturbances [14,15]. However, the complexity of the condition needs to be studied in a less fragmented manner to understand how these problems may interfere with the person's day-to-day experiences, relationships, and pursuits [8].

Experiencing a TBI can be conceptualised as a 'critical event' that disrupts the structure of everyday life; according to Bury, this experience may be labelled as a form of biographical disruption [16]. In the context of a health crisis, biographical disruption has been described as comprising three dimensions: the body, conceptions of self, and time. This theory suggests that an injury that leads to an inability to perform valued everyday occupations may lead to a loss of certain aspects of self, such as perceptions of competence, self-worth and identity [17]. Hammel [18] discussed the concept of biographical disruption and the two forms of meaning of impairment suggested by Bury [16]. First, the meaning of "impairment" can be viewed in terms of its consequences for everyday occupations and relationships. Second, impairment may be considered in terms of its symbolic significance, such as in its different social connotations [18]. These differences may have a profound influence on how individuals regard themselves and how they believe themselves to be perceived by others. Hammel argues that rehabilitation professionals tend to focus on the consequences of disrupted biographies and less on the significance of the impairment [18]. However, the impairments will necessarily influence an individual's perception of social worth and the potential stigma inflicted by society.

In a meta-synthesis of qualitative research on the experiences of recovery and outcomes after TBI, themes such as disconnection with a person's pre-injury identity, emotional and social problems, and a feeling of loss were identified [8]. A scoping review addressing self-identity and occupational identity after brain injury revealed that the experience of identity changes was extensive [19]. Self-identity is defined as an innate characteristic that includes the way in which individuals perceive themselves, including personal goals, values, and attitudes [19-21]. Occupation is broadly viewed as including activities or tasks that people perform, such as looking after themselves, enjoying life and participating in society [22,23]. In an occupational science context, meaningful occupation is considered to contribute to the construction and expression of self-identity [21,24]. Occupational identity refers to the way in which persons see themselves and their opportunities to participate in occupations that are culturally recognised [22,23].

Because many individuals with TBI are of working age [25], they are in danger of becoming non-productive as a consequence of their injury [26]. Work is strongly associated with agerelated role expectations and occupational identity [27]. Additionally, in Western societies, work and productive goal-oriented occupations are highly valued [28]. Persons with TBI have reported the process of returning to work to be both challenging and painful, with the experience of a loss of confidence in their worker roles [29,30] and a distinct grief reaction during the process of re-engagement in their occupation [31].

The ability to fulfil work obligations and the experience of a satisfactory work life may be highly dependent on how an individual organises and manages daily life in general [32].

Obtaining a balance in daily life between various daily occupations is essential [32-34]. Thus, there is a need for more insight into how individuals with TBI adjust to everyday occupations in the return-to-work (RTW) context. The aim of the present study was to explore TBI as a biographical disruption and to study the process of reconstructing everyday occupations and work participation among individuals with mild TBI.

## Methods

# Context of the study

This study was performed within an RTW context, i.e., a rehabilitation programme provided at a physical and rehabilitation medicine department in Norway. Patients with a protracted course of recovery after mild TBI were offered a multidisciplinary outpatient rehabilitation programme to support the return to work or the continuation of work. The programme included individual assessments and group sessions. In the first group session, the patients shared their problems, experiences and challenges related to living with and recovering from a TBI. The four subsequent group sessions focused on the following themes: mild TBI and brain functioning, cognitive impairment, physical activity, and, finally, daily activities and work. The expressed goal for the programme was enabling the patient to return to work as rapidly as considered appropriate by the patient and the rehabilitation team. The programme was part of a specialised, government-funded effort aimed at achieving a faster RTW for several groups of patients on sick leave.

# Study design

The context for the study was the first group session in the rehabilitation programme. A focus group methodology was chosen for two related reasons: to let the participants share and discuss their experiences of sustaining a brain injury and to gather qualitative data for use in studies. This approach is especially useful for studying complex issues that entail many aspects of feeling and experience, from the patient's perspective [35]. The interview guide was developed based on the WHO's [36] conceptual framework of human functioning and disability (ICF) in an attempt to address the complex condition of living with mild TBI [37].

The study was approved by the Regional Committee for Medical Research Ethics in the Eastern Health Region of Norway (approval # 171.08). The participants provided written informed consent and were informed about their right to withdraw without incurring any consequences regarding their further participation in the programme.

# Participants and injury characteristics

Persons between 18 and 60 years of age who had sustained a mild TBI and participated in the RTW programme were eligible for the study. Patients with severe pre-injury psychiatric disorders or a substance abuse history were excluded. Injury characteristics were described using the patients' GCS scores [5] and other information about the severity of the injury obtained from the medical record. The GCS is a scale for rating consciousness that assigns scores ranging from 3 (no response) to 15 (normal level of consciousness). Scores from 13-15 are associated with mild TBI. The level of consciousness was assessed on admission or at the site of the injury, or was based on information documented in the medical records. Mild TBI was categorised as uncomplicated or complicated, based on MRI or CT findings of the presence or absence of a structural brain injury.

In total, 20 patients were included in the study. The participants' demographic and injury characteristics are summarised in table 1. Nine participants had structural findings on CT/MRI that reflected more severe injuries.

## Insert table 1 about here

Twelve women and eight men, with an age range of 22 to 60 years, participated. Nine participants were classified as having a complicated mild TBI. At the time of the injury, all were 80-100% employed or in higher education. When the interviews took place, between 11 and 87 weeks after the injury, 12 participants had achieved partial or full employment. Four out of 20 were still on full sick leave 45 weeks or more after the injury.

## Procedure

Seven groups were successively formed as patients were enrolled in the rehabilitation programme and in the study. The group size was set at a maximum of four to five participants after taking into account the reduced capacity found in people with TBI with respect to concentration and fatigue [38]. The groups ultimately included three or four patients, with the exception of one group that had only two participants because the third person failed to participate in the meeting. Two groups included only female participants, and one group was exclusively male. All focus group sessions were conducted in a nondirective manner by two moderators, a physiotherapist (HLS) and an occupational therapist (US). Both had expertise in the field of TBI. The role as a moderator was used interchangeably. The moderator conducted the meeting and the discussions, while the co-moderator observed the interaction in the group and signs of fatigue or other discomfort.

The topics of the interview guide encouraged the participants to describe experienced problems in body functions, activities and participation. They were also asked about the factors in their environment or living conditions that they experienced as either facilitators or barriers to functioning and everyday life, including work life. An open approach was used in which the participants were asked to discuss their mental/cognitive and physical problems as well as their problems of everyday life [34]. The interviews were performed between November 2008 and April 2010.

The sessions started by asking the participants to provide a brief autobiography and to share with the group how the injury had happened; discussions followed regarding the participants' experiences, challenges, and coping mechanisms after sustaining the TBI. Due to common challenges after TBI of maintaining attention over time and experiencing fatigue, support was given by the moderator to keep the discussion on track, and take care that all participants got the chance to speak.

## Data analysis

The interviews were digitally recorded with an Olympus WS-331M device and transcribed verbatim. Data analysis was carried out using qualitative content analysis [39,40]. Although it was not a linear process, the analysis moved through the following stages: First, the interviews were read and discussed by the three authors to create a sense of the whole. Afterwards, the text was re-read, focusing on meaning units that reflected the aim of the study. Meaning units were extracted and condensed by creating codes close to the participants' own descriptions. All authors extracted and coded at least two interviews. The initial codes were compared across the interviews and refined into categories, whereby themes

started to emerge. This stage was initially performed by the third author (SO) and then discussed with the other authors (US and HLS). Finally, all the authors discussed the entire analysis and came to a consensus on four main themes and the excerpts that best illustrated these themes.

#### Results

Four interrelated themes emerged from the analysis: (1) disruption of occupational capacity and balance, (2) changes in self-perception, (3) the experience of time, and 4) occupational adjustment and reconstruction.

Disruption of occupational capacity and balance

Following mild TBI, the participants experienced an idiosyncratic mix of cognitive and affective impairments in the physiological and occupational domains. The meaning of the impairments lies in their impact on the individual's everyday occupations and relationships. The feeling of excessive fatigue, which was the most pervasive impairment affecting occupational capacity and balance, accompanied changes in cognitive ability, the ability to participate in work, and overall activity patterns. Fatigue was perceived as different from physical tiredness and was both unpredictable and overwhelming.

It costs me nothing to wear myself out physically, but when my head gets too full it is as if my head takes all the capacity. (Informant 1, male, 28 weeks since injury, complicated mild TBI, on full sick leave)

Excessive fatigue disrupts occupational balance, as more time and energy are required for rest. The participants reflected on how to balance rest and activity in everyday life to optimise recovery.

What is it actually, to rest? Is resting to take a walk? Does rest require work? Is rest industrious? To be social three times a week? Or is rest simply to lie down on the sofa covered by the duvet like when you have flu? (Informant 6, female, 45 weeks since injury, on full sick leave)

Other reported problems included the amount of time used to plan the accomplishment of daily activities. Difficulties with initiating, preparing and carrying out everyday tasks led to distortions of daily life routines and tasks.

It is in a way like this - that I have to make a schedule that 'today, I have to put on the washing machine'. I may use the whole day planning what to cook for dinner, you know. They are such silly things, but for me it is all about focusing on it, I may use the whole day on it [to do one simple task]. (Informant 13, female, 18 weeks since injury, on full sick leave)

Even if they made plans for activities throughout a day at home or at work, participants might be unable to complete the planned activities.

It is like when I'm at work, I plan that tomorrow I will do this and that, but the next day, this is not how it turns out. I may go home from work, not having done anything of what I had planned to do. The same [thing] happens in my daily life. (Informant 1, male, 28 weeks since injury, complicated mild TBI, on full sick leave)

Difficulties in managing daily routines and interpersonal relationships were also commonly explained by problems with concentration, memory and multi-tasking.

To "keep many balls in the air simultaneously" is a problem. This reflects [not only] on my study performance but also on how I organise everyday life with all that is going on. Remembering things for my children, remembering appointments, remembering what they have to do at school and during leisure time. To organise everyday life, that is not my favourite activity these days. (Informant 2, male, 60 weeks since injury, complicated mild TBI, full time student)

# Changes in perception of self

A sense of their past, present and future lives was created through the informants' sharing their own stories and listening to others. The consequences of the TBI challenged participants' pre-injury identity in different ways. All informants expressed a sense of loss - the feeling of a disruption of their former capabilities and their valued self-image. They were estranged from their pre-injury selves and not comfortable with how they experienced themselves after the injury, e.g., from being a very active person to sometimes experiencing total inactivity.

I used to be very active, active at work, active doing sports, well, active in general. I went from that to suddenly not bearing getting dressed, not bearing to take a shower, not bearing talking with anyone. So, this is just a completely new me, I do not recognise myself. (Informant 6, female, 45 weeks since injury, on full sick leave)

The many invisible symptoms of a TBI were perceived as a burden. The consequences would have been easier for family and friends to understand if the damage itself had been more visible, as in situations where plaster, casts, and crutches function as symbols of functional losses.

Significant differences in temperament or emotions, such as a decline in the intensity of feelings or a problem with control of emotions, led to a feeling of identity confusion and a drive to create meaning for such pervasive changes in personality.

Yes, you are not the same [as before the injury], you do not react in the same way anymore, my emotional life is levelled off, and this is so frustrating, particularly when you have a creative job where you need to find inspiration through your reflection on things. I've become just like a straight line and just have to acknowledge that this is life number two. I had the first before the injury, now I have a new one. (Informant 2, male, 60 weeks since injury, complicated mild TBI, full-time student)

I have an extreme anger that I am very embarrassed about. I've thrown quite a few things at the wall. I've never [been] like this before, and it seems like it is frustrating to me, I think, not being able to manage things, I cannot remember things, I'm so tired, I do not know how to handle it, I do not know who I should talk with [about this]. (Informant 6, female, 45 weeks since injury, on full sick leave)

The above excerpts also highlight the feeling of being left alone in the struggle of making sense of the perceived losses of self. The participants asked for more information and systematic follow-up from health professionals after discharge from the hospital.

I was there [acute stay in the hospital] for 4 days, was discharged and they said: "Just you contact us if there is anything". Ok, so then I went home and expect to get well soon. Instead, already when being discharged, you should have been told that this may take an incredibly long time. Prepare for it. You are not the same as you were. [....] You do not need to be told that this is how your life will be, but it may become like

that. I had a constant feeling of guilt because I was tired and because I could not go to work. (Informant 1, male, 28 weeks since injury, complicated mild TBI, on full sick leave)

As a consequence of having 'no one to talk with,' the participants spent a lot of time alone worrying about who they were and who and what they wished to become in the process of recovery.

## *The experience of time*

The process of remembering the past, experiencing the present, and anticipating the future gave rise to subjective awareness of disruption of the flow of time. The temporal orientation to recovery differed among the informants with respect to the degree to which they were stuck in the past, focused on the present, or were proactive and future-oriented. The individual mix of cognitive, emotional and affective experiences seemed to influence the perception of time, and the orientation towards time, as related to recovery. This seemed to influence the process of adaptation to the injury. Persons that were past-oriented seemed to experience more distress than those having a stronger future orientation, communicating more hope and optimism. All used their pre-injury situation as a reference for reflections and interpretation of the past, present and future by comparing their current capabilities with how they were right after the injury and somewhat later in the course of recovery. Thus, time also became a healing parameter when they experienced progress. The hope and longing to get better helped them to try to move on.

I notice a very different energy level when doing things now compared to before the injury. When it comes to the fatigue, this works a bit better for a while and then gets worse again. But I have noticed progress all the way, actually, in the last 5 months. So, this has made me feel quite optimistic, actually. Now I'm back in the study library. All my stuff was still there as I left them, actually. (Informant 17, male, 21 weeks since injury, complicated mild TBI, full-time student)

The subjective experience of time differed between the professionals and the informants. From a professional perspective, five months was still quite early in the recovery process; however, the informants experienced it as a rather long time. Uncertainty about the future, even losing control of the proximal future, seemed to pervade the entire process of psychosocial and occupational adaptations. Control was experienced as a fundamental part of recovery, and not knowing what to expect caused a feeling of despair.

They could have said that this is something that may take time. I came here [at the outpatient clinic] one month ago, and I was informed that I am still at an early stage, and 5 months had already passed [since the injury]. "For us you are at an early stage." Well, in my [mind] it should have been over in three weeks, three weeks after the injury, then I should have been [all the] way back again, and [yet] here I am six months afterwards". (Informant 1, male, 28 weeks since injury, complicated mild TBI, on full sick leave)

# Adjustment and reconstruction of daily occupations

Adaptations after a TBI manifest as a dynamic, unfolding and continuous temporal process of reconstructing daily life routines and occupations. The process involves improving functional capacity through effortful activity; refining values; rethinking the meaning of daily occupations, such as work; and the mobilisation of resources in the face of an altered situation. As this study was performed in an RTW context, issues related to work participation became crucial; however, the importance that was attributed to this topic varied among the

participants. Persons on long-term sick leave tended to discuss employment less than those who were employed or were in an earlier phase of the RTW course.

A variety of strategies for returning to or continuing with work were recognised. One strategy entailed going directly back to the pre-injury level of employment after some weeks on sick leave. This strategy could result in working more than 100% to be able to undertake the tasks involved in the previous workload. Thus, there may have been major personal costs of going back to work soon after injury. Participants were at risk of losing remunerative employment if they did not take control over the time spent at work or make other adjustments to the work situation.

I went back to work, yes, I think it was a week after the surgery (of a fracture). It was perhaps a little too early, and working not 100%, but 140% maybe. I've worked a lot. Things go more slowly, and I'm not as structured. I [used to spend] a very long time being able to get through the work day, but now I have taken a grip on this. So, for me now it is uphill all the way. Yes, I tell myself, "Now I leave at 4 o'clock, and it is not the end of the world". (Informant 5, male, 39 weeks since injury, working full-time)

I have become very sensitive to noise. At my workplace, there are many machines [making noise]. It did not use to bother me. Now, I need to take 5 minutes now and then, be in my own world to relax. (Informant 12, male, 11 weeks since injury, working full-time)

Participants returning to previous work hours generally experienced good dialogue with their managers and flexibility in their work situations. They were encouraged to take breaks and received acceptance for arriving late or leaving earlier if they had a bad day.

I have a pretty good dialogue with my boss, so he says to me that "once you start feeling unwell, just take a break, have a coffee, do what you need not to feel bad, and then continue to work." If I feel really bad, then I'm allowed to go home. That is no problem. The boss is very understanding. (Informant 11, male, 27 weeks since injury, working full-time)

However, not all the participants who returned to work after a few weeks on sick leave were ready for it. Such experiences led to a feeling of failure and occasionally to anxiety regarding unsuccessfully returning to work. However, the experience of going back on sick leave also depended on workplace support and the understanding of the consequences of the injury from work managers and colleagues.

I tried after 3 weeks, I really thought that I could have gone back to work after one week, but after three weeks, I felt guilty being ill. Then, I thought "I just have to try how it goes". However, I ought to have realised it when I could not even drive my car to work, I did not see the hint. Then, after 10 minutes at work, I realised that "this does not work". I could not focus, and I thought that "this is really not working; I just have to go home.". Then, I went back to be fully on sick leave for a while. It has taken a long time to recover after that. (Informant 16, female, 18 weeks since injury, complicated mild TBI, working full-time).

Yes, I have to say that I am very fortunate with my workplace. They are really supportive. They were the ones who pushed me to take sick leave. One of the managers has just been through the same thing and has friends as well who have been through the same thing. They said to me "unless you go home and sign up for sick

leave, you will get prolonged effects, and it will take a long time". (Informant 13 female, 18 weeks since injury, on full sick leave)

Another strategy, which was often more successful, involved a gradual return to pre-injury working hours. Even this strategy might imply the use of the subject's entire capacity to manage work obligations, at the expense of other daily occupations, family and social life.

I started working 20%, then there has been a gradual increase, and now I am working 60%. I get so tired, I sleep 12-13 hours, but I function well, to put it that way, while I'm working. My daughter understands very well. She comes home from school, and sometimes I am asleep, I am not spending time with her as before, unfortunately. I try the best I can. I miss not having enough energy. (Informant 3, female, 87 weeks since injury, on partial sick leave).

Moreover, a few participants who had been on sick leave for a longer period started a process of reconsidering their occupational values and a re-orientation in life. Choosing to take control over their lives became a relief in many ways.

The task I've had to put away, it's my job (...). So I'm happy that I got a 100% sick leave, because I really worked too much. Lots of work and little time for leisure. Actually, I had no real life. Now I use 100% of my time to try to make my everyday life as rewarding as possible. Work shall never again fill my whole life. (Informant 1, male, 28 weeks since injury, complicated mild TBI, on full sick leave)

In contrast with work and social life, which often were challenging, being outdoors, enjoying nature, and engaging in physical activities gave them energy to cope with other daily occupations and prevented depression.

The one thing that has been good for me was to be physically active...., yes, I really enjoy being outdoors; it gives me a lot of energy. (Informant 20, female, 39 weeks since injury, on full sick leave)

I read something about ... that a symptom [after TBI] could be depression. I know that the best pill against depression is to get out of the house, into the woods. So, I have wandered around in the woods, and this has kept the depression away. I noticed if I sit down one day and do not get out, then the sad thoughts come. Because I really want to get back to work, to see my friends, and to be quite normal. (Informant 20, 39 weeks since injury, female, on full sick leave)

## **Discussion**

Drawing on the conceptual framework of TBI as a disruptive experience, we explored how persons with a mild TBI who needed rehabilitation experienced the processes of adjustments and reconstruction of daily life. Because a brain injury affects a person's biography, it clearly has a temporal dimension in terms of past, present and future. The participants reflected on how time, in the sense of time that passes by, living with long-lasting functional problems became a burden in itself that influenced future planning. Whereas some participants seemed to still dwell on the past, others presented themselves as being on their way to restoring their pre-injury selves or as trying to restore their feelings of self-worth and building a new identity. The successful integration of past, present and future temporal aspects is considered to be paramount to the continuity of life activities, and is informed, among other factors, by

situational necessities and available personal resources [41]. Feelings of an uncertain and unpredictable future, even the proximal future, seemed to permeate the entire process of adjustments and reconstruction of daily life. This state of uncertainty can be interpreted as being in a liminal state, a period in which the person has lost one way of living and has yet to reconstruct a new way of being and acting in the world to enable biographical continuity [20]. In individuals being on long-time sick leave and less future oriented, there was a risk of a prolonged recovery process and lower motivation for returning to work. Health professionals may contribute to the process of reconstruction by enhancing motivation and supporting a gradual return to work and daily occupations.

Everyday life is the terrain for actions and interactions with other people in which individuals attempt to integrate the various roles and parts of their lives through these experiences. This integration crosses different social structures and roles, such as the private home, work life, parental duties, and leisure [42]. Sustaining a mild TBI seems to imply giving up several occupations that give structure, meaning, and purpose to life. An experience of giving up meaningful daily occupations that defined the participants' sense of self threatened their identity. There were also feelings of not recognising oneself, in the sense of not having the same capabilities or the same emotions as before. Referring to various pre-injury life situations, the informants depicted themselves as follows: 'a completely new me, I do not recognise myself,' or 'you are not the same.' A feeling of being left alone in their struggles of handling identity change and making meaning in their lives was described. They asked for systematic follow-up from health professionals to cope with the present situation and the future. This clearly addresses the fundamental work of rehabilitation, e.g., not only to focus on the consequences of disrupted biographies but also to incorporate the impaired body into a new sense of self.

Because work and productivity are highly valued in Western culture, work is closely linked to an adult's individual sense of self-worth. For the participants in our study, the drive to return to or continue work was troublesome, particularly for those on long-lasting sick leave but also among those who experienced success in re-entering their previous level of employment. Being on sick leave seemed to lead to a sense of guilt that might have pushed the participants back to work too early. Such a sense of guilt was reinforced by the fact that the symptoms of the TBI were not visible to others. For participants who returned to full-time employment too early, this strategy had significant personal costs, including living with extreme fatigue and forgoing family activities at home. For others, returning to full-time employment too early resulted in an experience of failure. These experiences, along with the more successful strategy of returning gradually to work, indicate the need for early and ongoing vocational support to be able to return to and continue in work.

Achieving a balance between various daily occupations (and obligations) is essential for an individual's health and well-being [32-34]. Occupational balance can be defined as "the individual's subjective experience of having "the right mix" (i.e. amount and variation) of occupations in his/her occupational pattern" [43]. In relation to occupational areas, all should be included; i.e. work/productivity, family and leisure activities, as well as rest and sleep. Excessive fatigue and the need for rest and sleep disrupted occupational balance in the participants. More time and energy were required to plan for the accomplishment of daily activities and the management of work obligations. This interfered with other aspects of everyday life, such as the abilities to take care of the home and family and keep up social relationships. These findings show the importance of paying attention to occupational balance in rehabilitation of persons sustaining a TBI [33]. In a study of Wagman et al., the participants

considered sleep to be important for life balance among working adults (33). Sleep has been discussed as having a dual relationship with occupational balance. Whereas insufficient sleep may cause imbalance, an imbalance may, in turn, cause sleep disturbance (33). This phenomenon is a well-known challenge in TBI [15], and was discussed in our focus groups. In TBI rehabilitation, interventions addressing sleep disturbances have been gaining increased attention [15,38]. Sleep hygiene techniques may assist in minimizing sleep disturbance, using a list of behaviors and environmental conditions aimed at improving sleep, as well as applying relaxation exercises, and sleep restriction therapies. Other non-pharmacologic treatments such as exposure to bright light, has also proven beneficial in daytime sleepiness, as well as physical conditioning programs [15,38].

The meaning of a disruption in occupational capacity and balance depends on factors such as personal values, life stage, personal roles, and interests, as well as economic and social resources [18]. Participants found various strategies to carry on and discover pathways to reconstruct their lives. Some started to redefine their values about social life and employment. Participants who were able to sense their own limits in their daily occupations – when to rest and how to plan their schedule for the day, including valued work and social occupations – described how this was helpful in the recovery process and in the reconstruction of a meaningful everyday life. Narrowing social life and giving up work for a defined period or more permanently could change from being a loss to becoming a turning point in the person's life, as they began to reconsider occupational values and re-orient their life, believing that work would not occupy their entire life ever again.

## **Conclusions**

This study explored disruptive experiences, adjustments, and biographical reconstructions in patients with a protracted course of recovery after a mild TBI. The meaning of the experienced impairments lies in their impact on the individual's everyday occupations and their symbolic significance for the individual. Successful integration of past, present and future was paramount to continuing life activities. The feeling of being left alone in their struggle to handle identity changes and find meaning in their lives indicates a need for systematic follow-up after hospital discharge. The troublesome journey of returning to work, often at the expense of other daily occupations, might be eased if all areas of daily life, as well as issues of identity and meaning, were addressed to support biographical reconstruction.

# Implications for rehabilitation:

- Individuals with a protracted recovery after a mild traumatic injury must reconstruct a new way of being and acting in the world to achieve biographical continuity.
- The perceived anxiety regarding changes in self and occupational identity, as well as loss of control over the future, can be attenuated through informational sessions during the hospital stay and at follow-up visits.
- The significant personal costs of returning to full-time employment too early indicate the need for early and ongoing vocational support in achieving a successful return to work.

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# **Declaration of interest**

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Table 1. Characteristics of the participants and injury-related information (n=20)

<b>.</b>	1
Characteristics	
Age, mean (SD)	40.3 (SD 10.3)
Range	22-60
Sex (n)	
Female	12
Male	8
Living situation (n)	
Cohabiting	15
Living alone	5
Education) (n)	
≤12 years	6
>12 year/University level	13
Unknown	1
Employment status at the time of injury	
(Working or studying) (n)	20
Sick leave at time of interview (n)	
Complete	8
Partial	3
None	9
GCS score, median, [IQR]	15 [14-15]
Injury mechanism (n)	
Traffic	9
Fall	7
Other	4
Weeks since injury, median [IQR]	30 [21-46]