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Patient-Reported Problem Areas in Chronic Traumatic Brain Injury

Ida M. H. Borgen, Cand. Psychol.; Ingerid Kleffeltgård, PhD; Solveig L. Hauger, PhD; Marit V. Forslund, MD, PhD; Helene L. Sjøberg, PhD; Nada Andelic, MD, PhD; Unni Sveen, PhD; Laraine Winter, PhD; Marianne Løvstad, PhD; Cecilie Røe, MD, PhD

Objective: The aims of this study were to (1) assess self-reported main problem areas reported by patients with traumatic brain injury (TBI) and their family members in the chronic phase, and (2) compare the self-prioritized problems with difficulties captured by questionnaires and neuropsychological screening through linking to the International Classification of Functioning, Disability and Health (ICF). **Setting:** Outpatient clinic at the Oslo University Hospital, Norway. **Participants:** In total, 120 patients with TBI were recruited, of whom, 78 had a participating family member. Eligibility criteria were a clinical TBI diagnosis with verified intracranial injury, living at home, aged 18 to 72 years, 2 years or more postinjury, and experiencing perceived TBI-related difficulties, reduced physical and mental health, or difficulties with participation in everyday life. Patients with severe psychiatric or neurological disorders or inability to participate in goal-setting processes were excluded. **Design:** Cross-sectional. **Main Measures:** Target Outcomes, that is, 3 main TBI-related problem areas reported by patients and family members, collected in a semistructured interview; standardized questionnaires of TBI-related symptoms, anxiety, depression, functioning, and health-related quality of life; neuropsychological screening battery. **Results:** Target Outcomes were related to cognitive, physical, emotional, and social difficulties. Target Outcomes were linked to 12 chapters and 112 distinct categories in the ICF, while standardized measures only covered 10 chapters and 28 categories. Some aspects of post-TBI adjustment were found to be insufficiently covered by the ICF classification, such as identity issues, lack of meaningful activities, and feeling lonely. **Conclusion:** The Target Outcomes approach is a useful assessment method in a population with chronic TBI. The standardized questionnaires capture the spectrum of problems, whereas the Target Outcomes approach captures the prioritized individual problems hindering everyday life after TBI. While the standardized measures are an irreplaceable part of the assessment, Target Outcomes ensures patient involvement and may help clinicians better tailor relevant rehabilitation efforts. **Key words:** chronic TBI, community-based rehabilitation, outcome measurement, Target Outcomes, traumatic brain injury

Author Affiliations: Department of Physical Medicine and Rehabilitation, Oslo University Hospital, Oslo, Norway (Ms Borgen and Drs Kleffeltgård, Forslund, Sjøberg, Andelic, Sveen, and Røe); Department of Psychology, Faculty of Social Sciences (Ms Borgen and Drs Hauger and Løvstad), Institute of Clinical Medicine, Faculty of Medicine (Dr Røe), and Center for Habilitation and Rehabilitation Models and Services (CHARM), Institute of Health and Society (Drs Andelic and Røe), University of Oslo, Oslo, Norway; Department of Research, Sunnaas Rehabilitation Hospital, Nesoddtangen, Norway (Drs Hauger and Løvstad); Departments of Physiotherapy (Dr Sjøberg) and Occupational Therapy Prosthetics and Orthotics (Dr Sveen), Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway; and M. Louise Fitzpatrick College of Nursing, Villanova University, Villanova, Pennsylvania (Dr Winter).

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TRAUMATIC BRAIN INJURY (TBI) can lead to a broad range of persistent difficulties, including deficits in physical, cognitive, emotional, and social functioning and quality of life.¹⁻⁴ While some regain preinjury levels of functioning, others live with TBI-related sequelae for many years, of whom some experience deterioration over time.^{5,6} More recently, TBI has been classified as a chronic disease with lifelong and dynamic consequences for health and well-being.^{7,8} Furthermore, in accordance with the International Classification of Functioning, Disability and Health (ICF)⁹ model, outcomes after TBI are influenced by personal

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Corresponding Author: Ida M. H. Borgen, Cand. Psychol, Department of Physical Medicine and Rehabilitation, Oslo University Hospital, Kirkeveien 166, Oslo 0450, Norway (idmbor@ous-hf.no).

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and environmental factors. As outcomes after TBI are heterogeneous, there is a need to identify each patient's specific difficulties and evaluate their individual rehabilitation needs.

There is a range of available measures suitable for patients with TBI, including questionnaires and performance-based tests. The use of standardized measures has many benefits, such as reliable assessment of clinically relevant symptoms, standardization across patients, access to normative data, and clinical cutoffs. Such measures are invaluable in diagnostic assessment but might not fully capture the patient's self-identified problems. Asking open-ended questions is necessary to ensure adequate measurement of prioritized TBI difficulties and individual tailoring of treatment. Furthermore, family members or others close to the patient should be asked to provide information about ongoing difficulties, especially since patients with TBI might have reduced awareness of their symptoms, and caregivers may have differing perspectives about the patients' everyday functioning. Wade¹⁰ argued that outcomes in rehabilitation research should also aim to address activity changes evident to the individual and their families to ensure the validity and feasibility of trials. However, there is a lack of consensus on systematic ways to collect self-reported high-prioritized problem areas in rehabilitation.

Gitlin and colleagues¹¹ proposed that assessing improvements in patients' main problems should be used to evaluate treatment effects in patients with dementia. They used Target Outcomes, which was based on the Target Complaints approach used in psychotherapy.¹² To measure Target Outcomes, patients and family members were asked open-ended questions about their 3 main problems and then rated their difficulty in managing the problem on a 10-point Likert scale. More recently, this approach was used as the primary outcome measure in a randomized controlled trial (RCT) of home-based rehabilitation for veterans with TBI by Winter and colleagues.¹³ The study showed a decrease in the difficulty of handling Target Outcomes in the intervention group. Furthermore, the Target Outcomes were categorized and showed disparities between patient and family reporting.¹⁴ The authors concluded that the Target Outcomes approach elicited novel insights into the challenges experienced in living with chronic TBI and were a sensitive measure of change in the ability to manage these symptoms. However, they did not systematically compare the information gained in Target Outcomes with that from established standardized measures. To enhance comparability of health information, linking procedures have been developed within the framework of ICF,¹⁵ which could be applied to analyze the conceptual content across patient-reported information and questionnaires.¹⁶

OBJECTIVES

An RCT inspired by the study of Winter and colleagues¹³ is currently being conducted in a sample of Norwegian civilians living with chronic TBI-related difficulties. This article aims to assess the utility of Target Outcomes by describing and categorizing the prioritized problem areas reported by the patients and family members. A second aim is to compare the patient-reported problem areas with symptoms captured by standardized questionnaires and a neuropsychological screening battery to assess the utility of Target Outcomes as a supplement to established measures by linking to the ICF classification. The hypotheses were that patients and family members would report Target Outcomes related to physical, cognitive, emotional, and interpersonal domains and that patient-reported Target Outcomes would capture problem areas not covered by the standardized measures.

METHODS

This article adheres to Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for observational studies.¹⁷ The study was approved by the Data Protection Office at Oslo University Hospital (OUH) (2017/10390).

Study design, setting, and participants

Data collection was part of a larger randomized controlled study evaluating the effectiveness of home-based rehabilitation in chronic TBI including 120 patients recruited at OUH in 2018-2020. The study protocol provides additional information regarding the study design.¹⁸ Inclusion criteria were age 18 to 72 years, a TBI diagnosis with computed tomography/magnetic resonance imaging-verified intracranial injuries 2 or more years ago, living in a noninstitutional setting, and reporting ongoing TBI-related difficulties, including reduced physical or mental health and/or reduced participation in daily activities. Exclusion criteria were severe neurological or psychiatric illness that would confound outcome, inability to cooperate in the goal-setting process (eg, severely reduced awareness and no available collaborators), insufficient fluency in Norwegian, or ongoing violent tendencies or substance abuse that would put study personnel at risk. If the patient had a close family member or friend whom they would like to participate, this person was included. The patients and family members provided written consent. This article presents cross-sectional data collected at study inclusion (pretreatment). This baseline assessment was conducted at OUH in an outpatient setting and took approximately 4 hours. The order of administration of questionnaires,

TABLE 1 Patient characteristics (*N* = 120)

All participants (<i>N</i> = 120)	Mean (SD)/ <i>n</i> (%)/ median (range)
Age, y	45.15 (14.44)
Number of men	85 (71%)
Education level	
≤10 y	10 (8%)
11-13 y	69 (58%)
14-16 y	24 (20%)
≥17 y	17 (14%)
TBI severity by GCS score ^{a,b}	9.3 (4.3)
Mild complicated	41 (36%)
Moderate	18 (16%)
Severe	54 (48%)
Time since injury, ^c y	4 (2-24)
Cause of injury ^d	
Transport-related accident	50 (43%)
Fall	39 (34%)
Violent incident	9 (8%)
Other (sports- or leisure-related) ^e	18 (15%)
Work status	
Full-time employment	30 (25%)
Part-time employment ^f	29 (24%)
100% disability pension	55 (46%)
Retired	6 (5%)

Abbreviations: GCS, Glasgow Coma Scale; TBI, traumatic brain injury.

^aGCS score: mild, 13-15; moderate, 9-12; severe, 3-8.

^b*n* = 113.

^c*n* = 119.

^d*n* = 116.

^eAll injury causes that could not be classified as a fall, transport-related, or violent incident were classified as "other" and included sports-related and injuries sustained during leisure activities.

^fPart-time employment was prioritized over part-time disability, that is, most of the participants in this category also received disability benefits.

semistructured interviews, and neuropsychological assessment was standardized across patients to avoid bias.

In total, 555 potentially eligible patients identified from outpatient department records were contacted by phone to evaluate eligibility. Of these, 101 did not respond, 137 reported no needs, and 135 declined participation. Furthermore, 33 were excluded by phone screening and 15 did not attend baseline despite initial consent. At baseline, 14 were excluded according to the eligibility criteria, resulting in a final inclusion of 120 patients and 78 family members. Sample characteristics are displayed in Tables 1 and 2.

Mapping to the ICF and linking procedures

To enable comparison between the patient reported main problem areas (Target Outcomes) and the standardized questionnaires and neuropsychological assessment (aim 2), we mapped the information to

TABLE 2 Family member characteristics (*N* = 78)

Participants with family members (<i>N</i> = 78)	Median (range)/ <i>n</i> (%)
Relationship to family members	
Spouse	58 (74%)
Parent	12 (15%)
Other	8 (10%)
Family member age, y	48.5 (19-76)
Family member work status	
Employed/student	58 (74%)
100% disability pension	10 (13%)
Sick leave	2 (3%)
Applying for work	2 (3%)
Retired	5 (6%)
Homemaker	1 (1%)
Time spent with participant	
Daily contact	66 (85%)
Weekly contact	10 (13%)
Less than weekly contact	1 (1%)
Unknown	1 (1%)

the ICF. We used the components "body functions" and "activities and participation" and second to fourth levels for more specified information (see Figure 1 for an overview of the ICF framework). This was done in accordance with established ICF linking rules¹⁵: the meaningful concepts of the patient-reported problem areas were identified and coded by 2 independent researchers (I.K. and C.R.). Linking of the standardized questionnaires and neuropsychological assessments was based on existing literature and supplemented by coding when necessary (I.K. and C.R.). Disagreements were resolved by consensus and in cooperation with a third researcher (H.S.).

Measures

Target Outcomes

Target Outcomes were derived from a semistructured interview. The patients were asked: "What is the main problem caused by your TBI that you have experienced in the past month?" Their open-ended responses were written down by the interviewers. This process was then repeated, eliciting the second and third most troubling problem areas. If a family member participated, the family member was also independently asked to report 3 main problem areas they considered most important for the patient. The interviews were conducted separately to ensure that both the patient and the family member felt free to provide their subjective perceptions, without consideration of the other's reaction. Target Outcomes were documented by the interviewer, with the wording being as close to the participants' choice of words as possible.

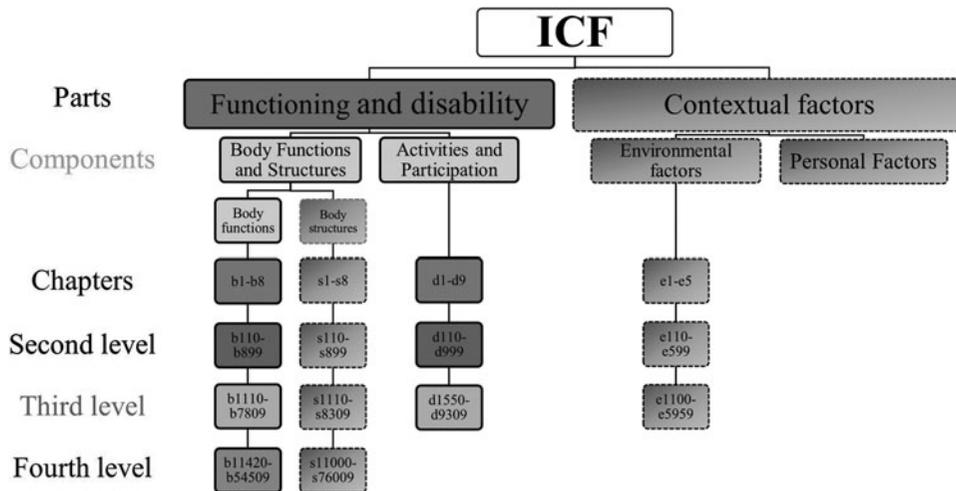


Figure 1. Structure of the ICF.⁹

Development of Target Outcomes categories

To address the first aim, a coding scheme was developed to categorize the individually reported Target Outcomes based on the written notes from the interviews. Two investigators (S.H. and I.M.H.B.) developed these Target Outcomes categories using the approach described by Winter and colleagues.¹⁴ This entailed that Target Outcomes categories were constructed so that similar problem areas were grouped together, e.g., tinnitus and visual deficits were grouped together within the category sensory difficulties, while being distinct from dizziness or motor impairments. The Target Outcomes categories were thereafter classified within distinct domains in accordance with Winter and colleagues, but one category (interpersonal) was renamed in accordance with the ICF model (social function and participation). The process of establishing data-driven Target Outcomes categories and domains was consensus-based, and disagreements were resolved by discussions in the research group.

In addition, the meaningful concepts of the Target Outcomes were identified on the basis of the written notes and linked to ICF. In total, 65% of the ICF categories were identified independently by 2 researchers (I.K. and C.R.) with complete overlap.

Standardized measures

Questionnaires

Standardized questionnaires were administered in their validated Norwegian versions (see Table 3). The questionnaires were chosen on the basis of the recommendations of Common Data Elements,⁴¹ measures in clinical use in Norway, and experience with problem areas of individuals with chronic TBI. Several of the standardized questionnaires had previously been linked

to the ICF (see Table 3). For 4 of the questionnaires (see Table 3), the existing linking was restricted to the component or chapter level and was in the present study supplemented with linking the meaningful concepts in the items to the ICF second- to fourth-level category according to the linking rules¹⁵ by 2 authors (I.K. and C.R.).

Neuropsychological assessment

Cognitive function was evaluated by a neuropsychological screening battery consisting of measures of auditory attention and working memory (Wechsler Adult Intelligence Scale-IV; WAIS-IV Digit Span),³⁵ verbal learning and memory (California Verbal Learning Test-II; CVLT-II),³⁷ abstract thinking (WAIS-IV Similarities and Matrices),³⁵ and psychomotor speed and executive functioning (Trail Making Tests and Color Word Interference Test from the Delis-Kaplan Executive Function System; D-KEFS).³⁸ Existing linking to the ICF was applied (see Table 3).

Data analysis and statistics

Statistical analyses were conducted in IBM SPSS version 25.0. Descriptive data for Target Outcomes categories are provided in number (%). The ICF categories linked to the Target Outcomes reported by patients were compared with the ICF categories linked to the standardized measures.

RESULTS

Aim 1: Target Outcomes domains and categories

All patients reported 3 Target Outcomes, while 5 family members only reported 2. Four domains were identified: (1) cognitive functioning, (2) physical functioning, (3) emotional functioning, and (4) social functioning and participation (see Table 4). Furthermore,

TABLE 3 Standardized measures with ICF chapters and categories

Measures	Assessment domains	ICF components and categories
Questionnaires		
Rivermead Post-Concussion Questionnaire (RPQ) ¹⁹ ; 16 items	TBI-related symptoms—physical, emotional, and cognitive postconcussive symptoms ²⁰	Body functions ²¹ ; <i>b130, b134, b140, b144, b152, b1600, b210, b21020, b2401, b28010, b280, b5350^a</i>
9-item Patient Health Questionnaire (PHQ-9) ²² ; 9 items	Depressive symptoms	Body functions ²³ ; <i>b122, b130, b147, b152, d175, d310^a</i>
7-item Generalized Anxiety Disorder (GAD-7) ²⁴ ; 7 items	Anxiety-related symptoms	Body functions; <i>b152²¹</i>
Patient Competency Rating Scale (PCRS) ²⁵ ; 30 items	Originally developed to assess self-awareness, also measures competence in daily activities ²⁶	Body functions ²¹ ; activities and participation (<i>d1-d9</i>) ²⁷ ; <i>b144, b152, b164, b3504, d355, d475, d540, d630, d640^a</i>
Quality Of Life In Brain Injury Overall Scale (QOLIBRI-OS) ²⁸ ; 6 items	Brain injury-related quality of life	Body functions (b1-b2); activities and participation (<i>d3-d9</i>) ^{29, b}
EuroQol-5D (EQ-5D) ³⁰ ; 5 items + VAS	Health-related quality of life	Activities and participation (<i>d4-d6</i>); <i>b152, b280³¹</i>
Participation Assessment with Recombined Tools—Objective (PART-O) ³² ; 17 items	Frequency of participation in 3 life areas: productivity, social participation, and community life	Activities and participation (<i>d6-d9</i>) ^{21, 33}
Behavior Rating Inventory of Executive Functioning—Adult (BRIEF-A) ³⁴ ; 75 items	Executive difficulties in everyday life	Body functions (b1) ²¹ ; <i>b140, b144, b152, b164^a</i>
Neuropsychological tests		
Weschler Adult Intelligence Scale-IV (WAIS-IV) ³⁵	Verbal and visual reasoning, auditory attention, working memory	Body functions; <i>b140, b156, b160, b167³⁶</i>
California Verbal Learning Test-II (CVLT-II) ³⁷	Verbal learning and memory	Body functions; <i>b144²¹</i>
Delis-Kaplan Executive Function System (D-KEFS) ³⁸	Psychomotor speed and executive functioning	Body functions; <i>b140, b164^{21, 31, 39}</i>

Abbreviations: ICF, International Classification of Functioning, Disability and Health; TBI, traumatic brain injury; VAS, visual analog scale.

^aAll items marked in italics are linked by the authors.

^bBased on the full version of the QOLIBRI.⁴⁰ The QOLIBRI-OS is less specific but was deemed to cover the mentioned ICF chapters, while more specific categories were not included.

24 Target Outcomes categories were established (see Table 4) within these domains. Patients and family members reported problems within all domains, while the most frequently reported problem categories were related to reduced capacity/fatigue, memory difficulties, and problems related to cognitive aspects of executive functioning.

Aim 2: Comparison between Target Outcomes and standardized measures

The meaningful concepts in the Target Outcomes were linked to 12 chapters and a total of 112 ICF categories, of which 61 of them were at the third or fourth level (see Supplemental Digital Content 1, available at: <http://links.lww.com/JHTR/A494>, and <https://apps.who.int/classifications/icfbrowser> for a detailed description of the categories). Meaningful concepts were

identified for all Target Outcomes. Yet, the wording and context of some of the expressed experiences were found to be insufficiently covered by the ICF categories. Specifically, this was relevant for lack of interest or apathy, identity issues, feeling worthless or like a burden, loneliness, lack of meaningful activities, inability to contribute, and difficulties accepting life changes. Although the standardized questionnaires covered 10 chapters of the ICF, only 28 second- to fourth-level categories were covered. The neuropsychological assessment covered another 4 second-level categories (see Supplemental Digital Content 1, available at: <http://links.lww.com/JHTR/A494>). When comparing the reported second-level ICF categories in the Target Outcomes with the standardized measures, a total of 20 (17%) patients did not have their body function issues covered and 67 (56%) did not have their activities and participation issues covered by the

TABLE 4 *Target Outcomes categories for patients (N = 120) and family members (N = 78)*

Target Outcomes categories by domain	Example	Patient, n (%)	Family, n (%)
Cognitive difficulties		92 (77%)	47 (60%)
Attention difficulties	Difficulties with concentration, distractibility	26 (22%)	9 (12%)
Reduced processing speed	Increased time to complete tasks	7 (6%)	2 (3%)
Memory difficulties	Forgetting appointments, tasks, or names	44 (37%)	18 (23%)
Visuospatial difficulties	Difficulties with navigating surroundings	2 (2%)	1 (1%)
Language difficulties	Word-finding difficulties, aphasia	6 (5%)	3 (4%)
Cognitive aspects of executive functioning	Difficulties with planning/organizing, problem solving, initiating tasks, mental flexibility, reduced awareness, impulsivity	35 (29%)	31 (40%)
Physical difficulties		97 (81%)	56 (72%)
Reduced capacity and fatigue	Reduced energy, mental fatigue, difficulties with initiating physical exercise	61 (51%)	38 (49%)
Pain	Headache, migraine, other pain	17 (14%)	11 (14%)
Sleep difficulties	Disrupted circadian rhythms, prolonged time to fall asleep, disrupted sleep	19 (16%)	7 (9%)
Difficulties with motor functions	Reduced walking function, reduced hand function	11 (9%)	6 (8%)
Sensory difficulties	Visual deficits, tinnitus, light sensitivity, noise sensitivity	18 (15%)	9 (12%)
Difficulties with dizziness and balance	Reduced balance, fall tendencies, vertigo	20 (17%)	9 (12%)
Difficulties with natural functions	Increased frequency of urination, reduced sexual drive	2 (2%)	1 (1%)
Emotional difficulties		46 (38%)	38 (49%)
Emotion perception and regulation	Mood swings, lack of empathy, emotional blunting, apathy	9 (8%)	8 (10%)
Irritability ^a	Anger, irritability at home, work, or while driving	13 (11%)	17 (22%)
Anxiety	Anxiety, worrying about the future	14 (12%)	6 (8%)
Depressive thoughts and feelings	Increased number of negative feelings, rumination, hopelessness	9 (8%)	7 (9%)
Difficulties with coping with stress	Difficulties handling unforeseen events, increased levels of stress	3 (3%)	2 (3%)
Difficulties with identity, acceptance, and sense of self	Changes in family roles, difficulties with own identity postinjury, feelings of worthlessness, loss of self-confidence, difficult to accept life changes	5 (4%)	6 (8%)
Social function and participation		29 (24%)	31 (40%)
Behavioral dysregulation	Socially inappropriate behavior, behavioral rigidity, acting childish	3 (3%)	9 (12%)
Social communication difficulties	Conflicts with other, difficulties communicating needs to others, difficulties taking turns in conversation, frequent misunderstandings	4 (3%)	10 (13%)
Reduced self-sufficiency	Difficulties managing own life, loss of driver's license, dependence on others	6 (5%)	1 (1%)
Reduced social participation	Spending less time with friends, loneliness	13 (11%)	16 (21%)
Lack of meaningful activities	Feeling like everyday life is "empty" and missing meaningful activities	4 (3%)	0 (0%)

^aIrritability was chosen as a separate category from "emotion perception and regulation" because it was reported frequently as a specific problem by both patients and family members.

standardized measures. When considering third- or fourth-level categories, 113 (94%) patients did not have their body function covered by the standardized measures and 27 (23%) patients had uncovered activities and participation concepts. This suggests that Target Outcomes covered several areas that the standardized measures missed.

DISCUSSION

The aim of this article is to assess the utility of the Target Outcomes approach for a population of civilians living with chronic TBI. We specifically wished to investigate *what information* this approach would elicit and further *how different* this information was from what is obtained by using standardized measures commonly used in the field of TBI.

The first aim was to describe and categorize prioritized problem areas reported by patients with TBI and their family members. The same domains were identified as in the study by Winter and colleagues,¹⁴ and in both studies, 2 of the most frequent responses were related to memory problems and difficulties with executive functions. However, the names of Target Outcomes categories identified differed somewhat between the studies, as did which difficulties included within each category. However, 18 of 24 categories were found to be comparable across the studies. The 6 nonoverlapping categories only reported by Winter and colleagues included poor self-care, obsessiveness, drinking problems, spending too much money, driving problems, and poor appetite. Instead, reduced mental speed, visuospatial difficulties, difficulty handling stress, difficulties relating to identity and acceptance, as well as lack of a meaningful everyday life, were identified only in our study. In addition, the Target Outcomes category with most frequent nominations in our study was fatigue. In the study by Winter and colleagues, fatigue was part of the category “other physical problems” together with dizziness, loss of dexterity, and seizures. Despite this, the category was only the fifth most frequent. These differences between the studies might be explained by individuals with more severe injuries being included in our population and perhaps differences between civilian and military populations. Our sample seems to be representative of civilian populations of patients with chronic TBI regarding injury severity and cause, as well as educational level, and about 50% being employed. In addition, cultural differences between the United States and Norway, as well as differing theoretical perspectives and professional background among researchers, might further explain the identification of somewhat differing Target Outcomes categories.

The inclusion of family member respondents was found to often provide more in-depth details about the

patients' level of functioning and broaden the perspectives provided by patients. The differing perspectives by patients and family members on what constitutes the main problems post-TBI might be important in guiding treatment planning. No distinct Target Outcomes categories were reported by family members beyond those that were reported by the patients themselves on a group level in the current study, while 10 categories in the study by Winter and colleagues were reported solely by family members. Previously, Winter and colleagues⁴² have described differing patterns of reporting for patients and family members relating to domains of functioning.

The second aim was to compare the Target Outcomes with the standardized measures. The results showed that Target Outcomes provided a more detailed problem description, that is, covering more ICF categories at all levels than the standardized measures. However, the ICF framework did have shortcomings regarding areas of functioning that were important to the patients with TBI, such as difficulties related to identity, loss of meaning, and loneliness. Thus, there seems to be a subgroup of patients experiencing their main problems in areas that could easily be overlooked if only relying on standardized measures. Issues related to identity, role changes, and psychological adaptation to a life with altered functioning are common. To summarize the issues at a group level, the measures need to combine personality, emotional, and higher cognitive functions, and in TBI research, this is perhaps best captured in qualitative studies,⁴³ as the issues are difficult to measure with objective standardized measures and will be unique to each patient. Importantly, these difficulties reflect disruptions of the adaptation to a life with chronic TBI symptoms, thus differing from emotional difficulties as seen in psychiatric disorders. Previous studies have documented limited access to services to address emotional difficulties post-TBI.^{44,45} Living with adjustment-related emotional symptoms after TBI may be long term and may at worst increase over time and lead to deterioration of mental health if these individuals do not meet the criteria for psychiatric treatment and if the rehabilitation services fail to acknowledge and address these problems. It is noteworthy that the ICF classification does not cover these issues that are important not only after TBI but also in the chronic phase of many injuries or diseases of varying causes. As patients in the current study were at 2 to 24 years postinjury, it is evident that these issues may remain undetected or inadequately treated for several years after injury, despite having received rehabilitation after TBI.

Clinicians usually talk with patients to identify their individualized needs and wishes; however, this process could be supported by using a structured approach such as Target Outcomes. Furthermore, the same approach

could be used to systematically collect information from caregivers, who additionally might have their own uncovered support needs. This approach could support clinicians in establishing a prioritized list of problems and enable the establishment of patient-centered treatment goals, which is in line with recommendations for rehabilitation, that is, that it should be patient-centered and goal-oriented.^{46,47}

The Target Outcomes approach could likewise be a useful addition to TBI research. TBI research frequently involves testing of specific treatments to ameliorate specific problems, often identified and measured by standardized questionnaires and neuropsychological evaluations. However, as demonstrated by the current study, these standardized measures and accompanying interventions might not capture and target the problems that patients and their families would prioritize as most important in rehabilitation. To ensure patient-centered research that is easily transferrable to clinical practice, this emphasizes the relevance of research on individualized intervention programs for patients with TBI. For patients with specific problems, the sensitivity of detection of change in rehabilitation target outcomes might be lower in standardized measures using summary scores that include items of varying relevance than for individualized measures directly targeting the problem. The Target Outcomes approach also includes a severity rating by the respondents, enabling assessment of change posttreatment relevant for both research and clinical practice purposes. Another outcome measure based on patient-reported difficulties recently shown to be applicable in a population of acquired brain injury⁴⁸ is the Patient Specific Functional Scale (PSFS).⁴⁹ However, the PSFS is activity-based whereas the Target Outcomes approach allows for the identification of a broader range of problems.

The Target Outcomes approach was found to be easily completed by both interviewers and respondents. It ensures that the user's perspectives are emphasized and might elicit specific difficulties of importance when planning rehabilitation for patients with TBI in their individualized context in the chronic phase. These results do not diminish the importance of standardized outcomes in research or clinical practice, as they are recommended in both diagnostic assessment and treatment planning.²¹ However, choosing relevant outcome measures for individuals with TBI can be a challenging task. Tate and colleagues²¹ identified 728 different outcome measures in the field of TBI in their systematic review and concluded that choosing outcomes might be especially difficult in cases of new or rare problems. As evidenced by the current findings and recognized in the field of TBI rehabilitation, neither use of the ICF nor the use of standardized measures guarantees that one obtains all relevant information

from the patient. This highlights the ingenuity of using the Target Outcomes approach in addition to the use of standardized measures in treatment planning to avoid burdening patients and families with an excessive number of questionnaires.¹⁰

LIMITATIONS

This is to our knowledge the first study to systematically compare information from open-ended questions to patients with TBI about their self-reported main problems with standardized measures. However, several limitations should be considered. First, our sample must be considered as a subgroup of patients with TBI who still experience difficulties at least 2 years postinjury, and the method is probably superfluous for patients experiencing only minor problems related to their injury, such as those with mild noncomplicated TBI (not included in the current sample). A second limitation is the choice of the ICF classification. Although the framework allows comparisons of different outcomes after TBI, the ICF framework does not capture all problems reported by the patients at the personal level, and other models that address issues outside the domains covered by the ICF should be considered. Furthermore, the standardized measures compared with Target Outcomes in this study are based on a selection of measures used in an ongoing RCT. The list of measures available for the TBI population is long,⁴¹ and other measures might capture areas of difficulties not covered by our selection. However, the quite large number of standardized measures in this study is based on recommended measures for the TBI population, and additional measures would have increased the burden to patients. Finally, the Target Outcomes were written down by interviewers and not recorded verbatim. This might involve some translational process by the interviewer; however, the framing of the question and the order of administration were standardized to reduce this bias. In addition, this interaction between the patient and the therapist mimics that of normal clinical practice, increasing the external validity of the study and making the results more easily transferrable to use in clinic practice.

CONCLUSION

The Target Outcomes approach was found to be useful in extracting individualized problems that were important to patients with TBI and their family members. The approach also seemed to elicit a range of difficulties not captured by the standardized measures used in research and clinical practice, such as difficulties relating to identity and adjustment to life post-TBI. Although standardized measures are crucial, there is a need for supplementary methods to guide targeted rehabilitation efforts in the chronic phase of TBI.

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