Tesis Doctoral

Descripción del funcionamiento en pacientes que han sufrido un Traumatismo Craneoencefálico: un abordaje integral basado en la Clasificación Internacional del Funcionamiento, la Discapacidad y la Salud.

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A mi padre (in memoriam),
a mi madre,
a mi abuela,
y a Niels.

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“The first function of a physician is to cure men and women of their diseases and to comfort when he cannot cure. But that is not enough. He must help to create a true science of the body and the mind of man”.

William Penfield 1958

“Some mechanism of consciousness discovered during electrical stimulation of the brain” Read before the Academy, November 18, 1957 and published in the Proceedings of the NATIONAL ACADEMY OF SCIENCES, February 15, 1958.

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1. Introducción

El traumatismo craneoencefálico (TCE) es la primera causa de discapacidad en gente joven lo que constituye un grave problema de salud no sólo en los países desarrollados sino también en los subdesarrollados. Según estimaciones de la Organización Mundial de la Salud (OMS) este problema lejos de desaparecer puede incluso incrementarse en los próximos años(Corrigan & F. M. Hammond 2013)(WHO s. f.).

El estudio y conocimiento de las consecuencias e impacto del TCE sobre una persona es complejo debido en parte a la gran heterogeneidad de factores implicados en su fisiopatología y en su proceso de recuperación. A continuación se resumen los cinco principales aspectos que justifican dicha heterogeneidad:

- Existe una variabilidad etiológica en tanto en cuanto el TCE puede resultar de un atropello, de un accidente de tránsito, de una lesión por arma de fuego, de una caída o incluso como resultado de una agresión, entre otras causas menos frecuentes.
- La fisiopatología que incluye desde una lesión focal hasta una lesión axonal difusa con diferentes áreas de implicación del parénquima cerebral condiciona secuelas diferentes. El daño secundario derivado del aumento de la presión intracraneal o derivadas de la hipoxia que constituirían el daño secundario varía en los diferentes individuos y según las medidas terapéuticas realizadas.
- Existe una variabilidad interindividual: hoy en día se sabe que existen individuos predispuestos genéticamente a tener un peor pronóstico en el daño cerebral (proteína S 100). Además, también es conocido el impacto que tienen ciertos factores como son la personalidad, el nivel de estudios previo, el entorno social y familiar sobre la recuperación y reinserción en la sociedad. Adicionalmente el factor edad tiene una implicación importante en la recuperación y pronóstico.
- El acceso a recursos sanitarios es heterogéneo según las poblaciones estudiadas ya que no todo el mundo tiene acceso a un seguro sanitario que garantice un tratamiento integral tanto en la fase aguda como en la fase de rehabilitación.
- La percepción de salud y de enfermedad por parte del enfermo son un aspecto subjetivo y propio de cada individuo.

Al margen de esta enorme variabilidad interindividual, las secuelas tras un TCE también varían a lo largo del tiempo por lo que la OMS considera oportuno tratar al TCE como una enfermedad crónica (Corrigan & F. M. Hammond 2013). Finalmente estas secuelas no sólo tienen repercusiones morbosas sobre el propio individuo, sino también sobre su familia y por extensión sobre el resto de la sociedad.

Todo esto tiene una gran implicación a nivel de salud pública, ya que obliga al desarrollo de planes estratégicos de salud encaminados en primer lugar a la prevención de los traumatismos y, una vez fracasadas las estrategias preventivas, a su tratamiento(Gerold Stucki et al. 2003; Gerold Stucki et al. 2007).

El fin último del conjunto de intervenciones en la rehabilitación del daño cerebral traumático es el de mejorar la funcionalidad global de los individuos que han padecido un TCE. Para ello es preciso partir de un modelo de discapacidad integral, que abarque no sólo los problemas médicos directamente relacionados con la lesión, sino también que sea capaz de capturar las repercusiones que aquellos tienen sobre las actividades que puede hacer una persona, tanto a nivel de la vida diaria como comer, vestirse, asearse o caminar, como las actividades que permitan su papel en la sociedad como son el retorno al trabajo, la relación con los amigos o las las relaciones familiares, entre otras (Gerold Stucki et al. 2007; Alarcos Cieza et al. 2011; Alarcos Cieza et al. 2009).

Para la consecución de esta empresa, el modelo biospicosocial de la enfermedad es el que en estos momentos puede facilitar la descripción del espectro funcional de un individuo con un TCE y la Clasificación Internacional de la Funcionalidad, de la Discapacidad y de la Salud (CIF) es una taxonomía que puede permitir describir el grado de funcionalidad de los pacientes con esta patología(A Cieza & G Stucki 2008).

Esta tesis tiene por objetivo identificar el perfil de funcionalidad de los sujetos que han padecido un TCE mediante el uso de una taxonomía neutra y global como es la CIF.

2. Marco teórico

2.1. Generalidades sobre el traumatismo craneoencefálico.

El TBIMS (Traumatic Brain Injury Model System) (TBIMS s. f.)define al traumatismo craneoencefálico (TCE) como una lesión sobre el sistema nervioso central ocasionada por una fuerza mecánica externa que es evidenciada bien mediante una pérdida de conciencia, por un período de amnesia postraumática o por la presencia de hallazgos neurológicos que pudieran ser atribuidos de forma razonable al TCE durante el examen físico o mental (Corrigan & F. M. Hammond 2013; Harvey & Close 2012).

La importancia del TCE radica fundamentalmente en que constituye un grave problema de salud pública ya que es la primera causa de discapacidad y de muerte en gente joven. Se estima que en Europa viven alrededor de 7.8 millones de personas, es decir un 1.6% de la población total con algún tipo de discapacidad secundaria a ello. (Ewert et al. 2004) (Langlois et al. 2006)

Estudios norteamericanos realizados en EEUU describen que 200 de cada 100.000 personas son ingresadas en hospitales como consecuencia de un TCE. De ellas la mayoría son traumatismos leves (131 de 200) siendo el porcentaje residual aproximadamente similar en los traumatismos graves y moderados. Otro estudio realizado en EEUU y fundamentado en la información obtenida de una base de datos nacional americana denominada Traumatic Coma Bank (K. S. G. Chua et al. 2007), describen que aproximadamente 52000 personas mueren al año como consecuencia de un TCE. La mortalidad global se estima que oscila en torno a un 33% en el caso de los TCE severos y desciende hasta una cifra de 2.5% en el caso de los traumatismos moderados. Un 2% de la población de EEUU vive con secuelas por haber padecido un TCE.(K. S. G. Chua et al. 2007)

En sí mismas, estas cifras son alarmantes pero es posible que las estadísticas estén incluso infravalorando un problema de mayor complejidad si se tiene en consideración que la mayoría estudios epidemiológicos se basan en diagnósticos hospitalarios y en numerosas ocasiones, los pacientes atendidos por urgencias no entran dentro de estas estadísticas. Así, aquellos pacientes con traumatismos menos severos como por ejemplo el TCE leve, definido como aquel en donde el resultado de la escala de coma de Glasgow oscila entre 13 y 15, pasarían desapercibidos. No en vano, en la década de los 90, Goldstein alertó del TCE leve como una nueva “epidemia silenciosa” (Goldstein 1990). Dos décadas después los estudios epidemiológicos siguen destacando estos hechos como limitaciones a tener en cuenta en sus estudios.

Etiología

Tradicionalmente, los estudios etiológicos del TCE dibujaban un perfil típico de paciente varón joven como susceptible de padecer un accidente de tráfico. En las gráficas de distribución por edades era evidente un doble pico en relación a la incidencia. El primer pico se describía en relación a las edades jóvenes de la vida en donde la realización de actividades arriesgadas o hábitos de conducción más temerarios así como abuso de sustancias tóxicas es más frecuente. En esta franja de edad la probabilidad de padecer un TCE es de una mujer por cada tres o cuatro hombres. El segundo pico lo constituirían aquellas personas mayores de 65 años en donde la probabilidad de caídas o traumatismos se ve incrementada por problemas funcionales secundarios a la edad tales como la pérdida de visión o movilidad reducida por artrosis, al uso de medicación que interfiera en los reflejos produciendo traspiés, caídas o alteraciones en la conducción. En esta franja etaria, la proporción por sexos tiende a igualarse.

Cabe mencionar también la asociación de drogas y consumo de alcohol con una mayor incidencia de TCE tanto por su asociación con accidentes de tráfico como por un mayor número de problemas relacionados con la violencia (Corrigan et al. 2012)

El desarrollo de políticas y de legislación que promueven una conducción más segura como por ejemplo la obligatoriedad del uso del casco, de los cinturones de seguridad, los asientos especiales para niños, la limitación en la velocidad durante la conducción, así como también la prohibición del alcohol son algunas de las medidas que han contribuido a disminuir la siniestralidad en las carreteras y como consecuencia el número de personas afectadas por TCEs (Neyens & Boyle 2012). Este año han sido publicados tres estudios epidemiológicos en donde por primera vez la etiología accidental superaba a la traumática en los países desarrollados y en donde el pico bimodal etario tiende a igualarse.(Feigin et al. 2013; Harvey & Close 2012; Roozenbeek et al. 2013). Este puede ser un ejemplo de cómo la legislación puede modificar los hábitos de la población y repercutir sobre su estado de salud.

Otro estudio muy relevante en materia de salud pública es el del grupo de Stein(Stein et al. 2010). En este estudio epidemiológico se realizó un metaanálisis que incluyó a 140000 pacientes durante un período de 150 años. Hasta la fecha es el estudio epidemiológico que abarca el período más largo estudiado y recopila la información comprendida entre los años 1885 y 2006. Stein observó que la mortalidad tras un TCE había descendido en alrededor de un 50% hasta alcanzar una fase de plateau en los últimos 30 años. Probablemente el hecho del desarrollo de las técnicas de imagen que permiten un diagnóstico precoz de complicaciones intracraneales y el desarrollo de las técnicas quirúrgicas así como una mejoría en la calidad y coordinación de los servicios de emergencia han contribuido a una estabilidad en la mortalidad inicial tras el TCE pero no han podido disminuir la morbilidad secundaria a los daños ocasionados.(McIntyre et al. 2013; Harrison-Felix et al. 2012) (Rosenfeld et al. 2012).

Costes

El gasto total resultante de un TCE es una incógnita ya que el análisis de datos es complejo debido a la gran variabilidad lesional así como las diferencias entre los tipos de rehabilitación requeridos y las diferencias en los países(J. Ponsford et al. 2013)(Hu et al. 2013; Graves et al. 2013). Además, al describir los costes que ocasiona el TCE, hay que tener en cuenta los costes indirectos como son la pérdida de capacidad laboral, la redistribución en los roles de la familia y el consumo de gasto social. Estos costes varían ostensiblemente según la población estudiada y su cálculo es complejo. Por ejemplo, no es lo mismo la potencial pérdida de un joven trabajador en un país desarrollado que en un país del tercer mundo. En este sentido, cabe resaltar que la mayor parte de la información disponible en relación a los costes y pérdidas generadas por los TCE son derivados de estudios en países desarrollados.

En el estudio realizado en Finlandia por Tuomoninen (Tuominen et al. 2012) los costes derivados de un TCE grave eran significativamente más altos que casos menos severos y se estimaba un coste de 1.19 millones de euros por paciente .

En España, el estudio publicado por García-Altés (García-Altés et al. 2012) describe los costos que genera un TCE se sitúan entre 1,079,223,688.66 y 3,833,752,692.78 euros.

Fisiopatología

De forma grosera, tras un TCE se distinguen una lesión primaria, causada por los efectos inmediatos del impacto sobre el cráneo y el cerebro, y una lesión secundaria puesta en marcha por la primera que incluye fenómenos de citoxidad, apoptosis, liberación de neurotransmisores al espacio extracelular, ruptura de vasos sanguíneos y posibilidad del aumento de la presión intracraneal con el consiguiente riesgo de aumentar el déficit de oxígeno (Blennow et al. 2012).

Con el advenimiento de la tomografía axial computerizada (TAC) y de la resonancia magnética nuclear (RMN) se describieron las lesiones focales y las lesiones difusas. El daño axonal difuso se describe cuando el paciente pierde el conocimiento y se encuentran microtraumatismos axonales sin lesiones parenquimatosas que comprometen a la sustancia blanca y suelen ser secundarios a mecanismos de aceleración y deceleración. Las lesiones focales resultan del impacto tisular directamente relacionado con la lesión.

Los hallazgos radiológicos más frecuentemente observados son las contusiones, seguidas de sangrados subaracnoideos, hematomas subdurales y hemorragias intracraneales.

2.2.1 Problemas clínicos secundarios al traumatismo craneoencefálico.

Como se anticipó al inicio de este documento, las secuelas tras el TCE son heterogéneas. En los traumatismos leves, los problemas se centran fundamentalmente en la esfera cognitiva y en síntomas físicos como mareos, vértigos o cefaleas que suelen desaparecer a los pocos meses tras la lesión. Los traumatismos graves destacan por los problemas de conciencia y pueden comprender también déficits motores y sensoriales, problemas endocrinológicos, crisis comiciales, déficits cognitivos o trastornos de la conducta. Todo ello contribuye a complicar la descripción del espectro funcional de los individuos que han sufrido un TCE dificultando la comparación entre pacientes y entre estudios y por tanto limitan la realización de estudios pronósticos. De hecho, una revisión de la literatura identificó más de 100 modelos sobre factores pronósticos implicados en el TCE (Perel et al. 2006).

El conocimiento sobre el pronóstico de una lesión es, después del diagnóstico y del tratamiento una de las responsabilidades que tienen los médicos ante los pacientes y sus familias. Una de las necesidades más importantes referidas por los familiares de pacientes que han sufrido un TCE es precisamente el conocimiento del pronóstico de la lesión y paradójicamente el desconocimiento del mismo o la falta de información sobre la lesión y sus repercusiones supone una frecuente queja por parte de los familiares(Hélène Lefebvre & M.-J. Levert 2012).

Una encuesta realizada en 2005, encontró que el 80% de los médicos consideraba que el conocimiento del pronóstico funcional tras una lesión era importante a la hora de toma de decisiones de ciertas actitudes terapéuticas como el uso de barbitúricos, ventilación mecánica o cirugía así como también para determinar cuándo se debería de retirar un tratamiento (Perel et al. 2007). El conocimiento del pronóstico por parte de las familias facilita que éstas tengan más dominio sobre la situación y se preparen para las circunstancias adversas que puedan sobrevenir. El mismo autor constató que sólo el 37% de los médicos encuestados reportaban acertar en el diagnóstico. La falta de información pero también los fallos a la hora de dar el pronóstico, sobretodo en las fases agudas, mina la confianza depositada en los profesionales médicos y probablemente influirá sobre la relación médico-paciente-familia a lo largo del proceso de recuperación.

Los aspectos más relevantes a tener en cuenta en relación al pronóstico de una lesión se pueden clasificar en aquellos relacionados con las características del paciente, características clínicas tras la lesión, características radiológicas de la lesión y características clínico funcionales durante la evolución.

Los pacientes en las edades extremas de la vida como la infancia o la vejez suelen tener peores pronósticos. Aquellos pacientes pertenecientes a clases socioeconómicas más altas y con una reserva cognitiva previa también suelen evolucionar mejor.

La severidad de la lesión medida por la escala de coma de Glasgow (GCS), la asimetría pupilar y la presencia de hipertensión endocraneal así como el hecho de tener una lesión extracraneal grave asociada sugieren un mal pronóstico.

En cuanto a los hallazgos de las pruebas de imagen, parece que la existencia de hemorragia subaracnoidea, desplazamiento de la línea media, comprensión de las cisternas y hematoma subdural en el TAC se asociaban a un peor pronóstico. La presencia de un daño axonal difuso en la RMN también son signos de peor pronóstico y las lesiones más profundas (Borg et al.2011).

Bombardier y Mazzini (Bombardier et al. 2010; Mazzini et al. 2003) describen que la aparición de depresión y de crisis epilépticas tras un TCE son también factores con un impacto negativo.

La amnesia postraumática (APT) es el período de despertar tras una lesión y que se caracteriza por una alteración en la memoria anterógrada con desorientación y problemas de atención. Esta fase que habitualmente se mide con el test Galveston Orientation and Amnesia Test (GOAT) es otro de los factores relacionados con el pronóstico (J. Ponsford et al. 2008).

Otros autores como Boake, Sherer y Sigurdardottir (Boake et al. 2001; Mark Sherer et al. 2010; Solrun Sigurdardottir et al. 2009) consideran que la presencia de alteraciones neuropsicológicas a nivel de la atención, memoria y enlentecimiento de la velocidad de procesado de la información son factores de mal pronóstico y que disminuyen la calidad de vida con una alta probabilidad de imposibilitar el retorno al trabajo y a las actividades habituales de la vida previa.

Sin embargo, aún es preciso profundizar en el estudio más detallado sobre los factores pronósticos que permitan en una fase inicial predecir a medio y largo plazo el resultado funcional. Algunos autores, de entre los que destacan Husson reinvidican la necesidad de realizar estudios pronósticos multidisciplinares que tengan en cuenta aspectos neuroquirúgicos, neurológicos y rehabilitadores(Husson et al. 2010).

Trastornos de la conciencia

La pérdida de la conciencia, es la manifestación más visible inicialmente tras un TCE severo. La conciencia ha sido objeto de estudio por parte de los médicos y de los filósofos desde los albores de nuestra historia. Tal vez, si Descartes viviese hoy en día y dispusiese de los avances tecnológicos tales como la resonancia magnética cerebral funcional o estimulación magnética transcraneal hubiese concebido su célebre *cogito ergo sum* de otra manera.

La taxonomía en relación a los estados de alteración de la conciencia también ha variado a lo largo de la historia. Sobre los años 70, Jennet y Plum propusieron la definición de *estado vegetativo* como aquel estado en el que los pacientes mantenían sus funciones vitales preservadas con un estado de alerta que podía mantenerse durante un período largo, pero sin ser capaz de objetivar respuestas que supusiesen una actividad mental. Recientemente este término ha sido sustituido por el término de *estado de vigilia sin respuesta*, por considerarlo más apropiado y sin la connotación negativa que se asocia a la palabra “vegetativo” (Cologan et al. 2013; Noé-Sebastián et al. 2012).

Un eslabón inmediatamente superior al anterior, en donde los pacientes pueden tener unas conductas volitivas como por ejemplo el seguimiento de la mirada o seguir una orden sencilla como apretar una mano, fue descrito en 2002 por Giacino como de *estado de mínima conciencia*(J. T. Giacino et al. 2002)(John Whyte & Nakase-Richardson 2013).

Trastornos conductuales

Los trastornos conductuales en términos del impacto sobre el paciente, su familia y en definitiva la sociedad, son devastadores. Muchos pacientes que han sufrido un TCE leve y la gran mayoría de los TCE moderados y severos sufren secuelas conductuales que permanecen a largo plazo y que constituyen una gran limitación en el desarrollo de la vida de estos individuos (McNett et al. 2012)(Nott et al. 2006)(Levy et al. 2005).

Al margen de los episodios de confusión y agitación típicos de la fase de amnesia postraumática que generalmente ocurren durante la fase del despertar, los pacientes con TCE tienen un riesgo aumentado de padecer trastornos de ansiedad, episodios psicóticos, trastornos obsesivos compulsivos, depresión y abuso de sustancias (Castaño-Monsalve et al. 2013; Graham & Cardon 2008).

Trastornos motores

Los déficits motores suelen ser evidentes en los pacientes que han sufrido un TCE grave(Williams et al. 2009)(Williams et al. 2013; Williams et al. 2004; Bland et al. 2011). Según el área motora implicada el déficit motor puede implicar desde una a todas las extremidades corporales. En aquellos casos en donde la pérdida de fuerza es importante y en aquellos pacientes con desórdenes de conciencia severos, la falta de movimiento puede generar complicaciones derivadas de la inmovilidad como el riesgo de úlceras, pérdida de masa muscular, contracturas articulares, alteraciones cardiorrespiratorias, trastornos digestivos e incluso puede favorecer el desarrollo de una enfermedad tromboembólica. (Bratton et al. 2007; Ekeh et al. 2010)

También son conocidos los efectos que tiene la inmovilidad sobre el sistema cardiovascular, respiratorio, inmunológico y hasta incluso sobre el rendimiento cognitivo ya que el descanso prolongado en la cama se asocia con un impacto negativo en el rendimiento cognitivo (Nathan Zasler,Douglas Katz, Ross Zafonte 2013).

Tal vez menos llamativos en las fases iniciales porque son enmascarados por la alteración en el nivel de conciencia o en la fuerza, son los trastornos del movimiento como las distonías, el temblor o la ataxia. Estos trastornos pueden incluso empeorar a lo largo del tiempo llegando incluso a ser más discapacitantes que la propia pérdida de fuerza.

Pero sin duda, la complicación más frecuente que altera no sólo el movimiento sino que puede provocar dolor, generar deformidades musculo esqueléticas y puede conducir a una limitación en los cuidados como el aseo, la sedestación y el vestido son los signos derivados de la hiperactividad de la motoneurona superior, conocida como la espasticidad. (E. P. Elovic et al. 2004)(Esquenazi et al. 2012).

Alteraciones en los pares craneales y órganos de los sentidos

Las lesiones de los pares craneales se asocian frecuentemente al TCE y reflejan, de alguna manera, la severidad de la lesión ya que pueden implicar un compromiso del tronco del encéfalo. Su incidencia aumenta en aquellos pacientes en donde hubo asociado un traumatismo facial y elevación de la presión intracraneal (Cilo et al. 2010; Cockerham et al. 2009; Kelts 2010; Berryman et al. 2010).

El par craneal que se afecta con mayor incidencia es el nervio olfatorio, seguido del nervio facial y de los oculomotores. (M. Drummond et al. 2013; Solrun Sigurdardottir et al. 2010)

Sin embargo, los problemas de visión son los que más frecuentemente describen los pacientes o que mayor repercusión funcional tienen durante la realización de tareas de rehabilitación.

Estos problemas incluyen diferentes etiologías entre las que cabe destacar desde lesiones en los globos oculares de origen traumático, problemas en la musculatura extrínseca ocular pero también problemas en el nervio óptico. Si además se añade el hecho de que la vía visual tiene conexiones con la mayoría de áreas cerebrales y que la mayoría de TCES sufren de una lesión axonal difusa no es ilógico pensar que la vía visual se vea comprometida conduciendo a provocar déficits no sólo a nivel de campo visual sino también en la percepción y codificación por alteración en las áreas visuales secundarias.

Habla, lenguaje y deglución

Los problemas de comunicación tras el TCE son también notables y son además un factor crítico que afecta a la calidad de vida. Los problemas del lenguaje pero también problemas en el habla como la disartria, el temblor del habla o tartamudeo condicionan por sí mismos una dificultad en el retorno al trabajo y en la capacidad de mantener relaciones con el resto de la sociedad (Toyoshima et al. 2011; Baguley et al. 2004)(Lundgren et al. 2010).

La disfagia y los problemas deglutorios no son desdeñables y su existencia puede derivar en complicaciones que comprometan la salud y la vida del paciente. En la fase aguda y en estados de disminución de la conciencia es necesario la nutrición por vías alternativas como son las sondas nasogástricas o las sondas de gastrostomía. Pero en fases posteriores no es raro observar apraxias que dificultan la fase oral o alteraciones en los mecanismos de la deglución que ponen al paciente en una situación de riesgo de aspiración (R Terré & F Mearin 2009; Rosa Terré & Fermín Mearin 2007).

Epilepsia

Los TCEs son los responsables de un 5% de todas las crisis epilépticas (Cerniauskaite et al. 2012)(Chen et al. 2009; Christensen 2012). Las crisis precoces son aquellas que ocurren dentro de la primera semana tras el TCE y son generadas por la irritabilidad que ocasiona la liberación masiva de neurotransmisores al espacio extracelular. En ese momento la prevención farmacológica es necesaria. Transcurrida la fase aguda existe un riesgo de padecer crisis epilépticas que oscila entre un 35 y un 69% según los estudios. A este tipo de comicialidad se la denomina Epilepsia Postraumática (EPT)

Parecen existir algunos factores desencadenantes de la EPT como la hidrocefalia, la sepsis, ciertas alteraciones metabólicas o la hipoxia pero también algunos agentes farmacológicos dopaminérgicos empleados para mejorar el nivel de respuesta tales como la bromocriptina o la amantadina parecen disminuir el umbral epileptógeno. De todas formas, estudios recientes refieren que la incidencia de estas complicaciones es anecdótica. Fármacos de uso común como el tramadol empleado concomitantemente con antidepresivos tricíclicos parece que también puede favorecer el desencadenamiento de una crisis.

El hecho de padecer crisis epilépticas probablemente empobrezca el pronóstico funcional. Mazzini describió en su investigación que la EPT se correlacionaba con un peor pronóstico funcional evaluado con la GOS (Glasgow Outcome Scale), la DRS (Disability Rating Scale), la FIM (Functional Independence Measuremente) y tests neuroconductuales al año de la lesión (Mazzini et al. 2003; Chen et al. 2009; Christensen 2012).

Problemas neuro-ortopédicos

Las alteraciones neuro-ortopédicas pueden ser secundarias a traumatismos asociados al propio TCE como fracturas pero también como consecuencia de la espasticidad o del encamamiento.

Un problema frecuente es el dolor de hombro, cuya causa suele ser una amalgama de factores como son la inmovilización, el dolor regional complejo, subluxación inferior o espasticidad con adducción y rotación interna así como capsulitis traumática u osificaciones.

Las fracturas de huesos que pudieron acontecer durante la fase aguda son susceptibles de sufrir un retraso en la consolidación y su tratamiento puede estar condicionado al status neurológico del paciente como puede suceder en pacientes con importante espasticidad o agitación que impida un correcto cuidado tanto a nivel de tratamientos conservadores como quirúrgicos.

También se observa con una frecuencia en torno al 17% las osificaciones heterotópicas con tendencia a aparecer en caderas, rodillas y hombros. (J.-A. L. Aubut et al. 2011; Dizdar et al. 2013; van Kampen et al. 2011).

En definitiva, los problemas musculoesqueléticos son frecuentes y juegan un rol importante en la funcionalidad tanto a corto como a largo plazo por lo que las intervenciones ortopédicas tras el TCE constituyen a menudo una de las partes implicadas en el equipo multidisciplinar que trata a esta población. La elección del tratamiento quirúrgico sigue los principios de la traumatología pero teniendo en consideración de qué beneficios funcionales cabe esperar tales como la búsqueda de la mejora en la higiene o facilitación en la realización de las actividades de la vida diaria.

Hiperactividad simpática paroxística

Este es el término recientemente acuñado para denominar lo que anteriormente se describía como tormenta simpática, crisis adrenérgicas o disautonomía (Fernandez-Ortega et al. 2012; I. Perkes et al. 2010; I. E. Perkes et al. 2011; Baguley et al. 2009)(Laxe et al. 2013). Tras una lesión cerebral puede darse un espectro de síntomas derivados de una actividad simpática excesiva que se traducen en un aumento de la frecuencia cardíaca y respiratoria, fiebre, aumento de espasticidad que pueden durar desde unos minutos a varias horas. Entre un 62 y un 92% de los pacientes con un TCE grave pueden sufrirlo a lo largo de su convalecencia.

Trastornos del sueño

Hasta un 70% de los pacientes con TCE han sufrido al menos algún episodio de trastorno del sueño. Un 45% de ellos puede tener alteraciones en la polisomnografía con cambios en la tensión arterial e incluso apneas del sueño que incrementan la morbimortalidad (Huang et al. 2013; J. L. Ponsford et al. 2013; Mollayeva et al. 2013)

Trastornos neuroendocrinos

Diversos estudios hablan sobre trastornos endocrinos tras los TCE de entre los que destaca el hipopituitarismo (Kokshoorn et al. 2010). La hormona que más frecuentemente se altera es la hormona de crecimiento(Wagner et al. 2010)(Rothman et al. 2007) (Ulfarsson, Arnar Gudnason, et al. 2013), pero particularmente significativo es el déficit de hormonas gonadotrópicas por su implicación en la vida sexual y reproducción. Por otro lado, la secreción inadecuada de hormona antidiurética puede comprometer el balance hidroelectrolítico en un paciente cuyo nivel de conciencia no le permita identificar la sensación de sed.

Fatiga

Esta constituye otra queja típica de los pacientes con un TCE. Su incidencia oscila entre un 21 y un 73% según las series(Belmont et al. 2009). Los mecanismos subyacentes a la misma son desconocidos. No parece correlacionarse con el hecho de que exista depresión, pero sí que justifica una mayor alteración en la realización de las pruebas neuropsicológicas. Estudios con resonancia magnética funcional, ponen de manifiesto una mayor activación encefálica en los sujetos que han padecido un TCE en relación a sujetos sanos. Estos hallazgos pueden justificar la hipótesis de que una mayor activación cerebral promueve un gasto metabólico mayor y por tanto esto se puede traducir en una mayor fatiga mental a la hora de realizar una tarea (Kohl et al. 2009; Scheibel et al. 2007)

Hidrocefalia

El aumento de líquido cefalorraquídeo en los ventrículos es una complicación relativamente frecuente tras el TCE que puede aparecer en las primeras semanas pero también meses o incluso años más tarde. La hidrocefalia puede generar aumento de la presión intracraneal pero también hay casos de hidrocefalia normotensiva (Mazzini et al. 2003). Estudios describen un aumento de la mortalidad en aquellos pacientes que padecen una hidrocefalia(John Whyte et al. 2013).

Enfermedades neurodegenerativas

Existe una creciente evidencia que sugiere que los cambios estructurales y bioquímicos tras un TCE actúan como desencadenantes en el desarrollo de enfermedades neurodegenerativas como son la enfermedad de Alzheimer u otros tipos de demencia(Shively et al. 2012; Sivanandam & Thakur 2012; Van Den Heuvel et al. 2007).

Trastornos sexuales

Entre un 40 y un 60% de los pacientes que han sufrido un TCE manifiestan problemas de tipo sexual. Al margen de los problemas de hipogonadismo comentados con anterioridad que tienen su papel protector sobre osteroporosis y funcionamiento, la disfunción sexual juega un papel muy importante sobre la calidad de vida (Hanks et al. 2013; Moreno et al. 2013; Murphy & Elias 2006).

Incontinencia

Tanto la incontinencia urinaria como la fecal constituyen un problema médico con una gran repercusión social. Un 16% de los pacientes evaluados (Safaz 2008 obtenido de Massel) eran incontinentes urinarios al año de la lesión y un 14% (Sagaz 2008) eran incontinentes fecales (K. Chua et al. 2003).

Además de las limitaciones en la participación en actividades sociales, la incontinencia puede suponer un riesgo en el desarrollo de infecciones urinarias y complicaciones en el manejo de la piel.

2.2.2 Impacto del traumatismo craneoencefálico.

El capítulo anterior describía la pérdida de la función o la anomalía en la estructura de los sistemas corporales que aparecía como consecuencia del traumatismo craneoencefálico. Esta alteración corporal produce una alteración a nivel de la funcionalidad entendiendo por ésta un concepto amplio que incluye la capacidad individual para realizar las actividades básicas de la vida diaria, capacidad de retorno al trabajo pero también la posibilidad de participación en actividades lúdicas, paradigmas todos ellos de la independencia funcional y responsables en gran medida de la percepción subjetiva de calidad de vida (Braden et al. 2012; Jacobsson et al. 2010). A partir de los seis meses tras la lesión, cuando las características de perfil más físico suelen estabilizarse, los problemas de índole psicosocial se vuelven más evidentes e interfieren en la limitación de las actividades y restricción en la participación. El número de encuentros sociales disminuye en los individuos con secuelas con un TCE. Estudios como el de Ralph y el de Segal evidencian una pérdida de amistades previas y una dificultad en adquirir unas nuevas nuevas, lo que conlleva a una pérdida de participación en actividades lúdicas y conlleva a un mayor aislamiento (Ralph & Derbyshire 2013; Segal et al. 2002).

Otra de las consecuencias directamente relacionadas con las secuelas tras un TCE es la dificultad o incluso incapacidad para el retorno al trabajo habitual o trabajo remunerado. Es tal la importancia del retorno al trabajo, no sólo a nivel individual sino también social, que hoy en día se acepta el retorno al trabajo como uno de los indicadores del éxito de los tratamientos de rehabilitación tras un TCE(Radford et al. 2013; Esbjörnsson et al. 2013; Hooson et al. 2013).

Desafortunadamente, son numerosos los estudios que concluyen que las cifras de retorno al trabajo tras un TCE son extremadamente bajas. En un estudio reciente publicado por Jourdan (Jourdan et al. 2013), se refleja que sólo un 40% el porcentaje de los pacientes evaluados fueron capaces de adquirir una actividad remunerada tras el TCE. No obstante, los autores alertan de que estas cifras pueden ser poco realistas si se tiene en cuenta que parte de esa actividad remunerada se trata en realidad de trabajos inestables o por períodos escasos de tiempo.

Autores como Jordan, Radford y Temkin describen como predictores favorables de retorno al trabajo una buena situación marital, buen status socioeconómico, educación superior y un buen status laboral previo al trabajo así como menor lesión y menor tiempo de ingreso hospitalario(Jourdan et al. 2013; N. R. Temkin et al. 2009; Radford et al. 2013).

Otro de los aspectos altamente preocupantes y discapacitantes es la imposibilidad de volver a conducir. El padecimiento de crisis epilépticas, la necesidad de recibir cierta medicación, la existencia de problemas visuales o limitaciones motrices así como aspectos cognitivos como son déficits de atención, de velocidad de procesado de la información, alteración de las funciones ejecutivas o problemas de conducta, son algunos de los ejemplos limitantes para retornar el hábito de la conducción con la limitación que esto conlleva a la hora de relaciones sociales o incluso de acceso o desplazamiento al trabajo(Truelle, Fayol, et al. 2010; Liddle et al. 2011).

Calidad de vida

La noción de calidad de vida es un concepto multidimensional que fundamentalmente integra la sensación subjetiva de bienestar. Indudablemente se ve alterada como consecuencia de un TCE. Forslund, señala la percepción de una estabilidad en relación a la sensación de satisfacción con la calidad de vida de los pacientes con TCE entre el año y los dos años tras la lesión(Forslund et al. 2013; N Andelic et al. 2009; M. P. Dijkers 2004; Jacobsson et al. 2010; Nichol et al. 2011). Además, este grupo describe que aquellas personas que puntúan mejor en la calidad de vida suelen ser personas jóvenes con altos niveles de integración en la comunidad, con mejor salud y con menor puntuación en las escalas de depresión. Paradójicamente, aquellos con traumatismos más severos puntúan mejor, pero este hecho ya es ampliamente conocido entre los profesionales de personas con TCE por la típica ausencia de conciencia de déficit que tienen muchos de estos pacientes. (Forslund et al. 2013; Albrecht & Devlieger 1999)(Braden et al. 2012)

El grupo de trabajo de Dikmen encontró que un porcentaje elevado de personas que habían padecido un TCE describían problemas en el pensamiento y memoria, incapacidad de regresar al trabajo, obtención de ingresos económicos y alteración en la realización de actividades de tiempo libre como aquellas que más impacto negativo ocasionaban sobre la calidad de vida(Machamer et al. 2013). De forma similar, el grupo de Carlozzi identificó como parámetros que influenciaban negativamente la satisfacción personal y sensación de bienestar, problemas emocionales, de función social, física, cognitiva y cambios personales(Carlozzi et al. 2011).

Un estudio reciente publicado por Cieza y colaboradores analiza cómo los factores psicosociales impactan el resultado a corto medio plazo en enfermedades neurológicas como el ictus, depresión o traumatismo craneoencefálico (Alarcos Cieza et al. 2013) y como los profesionales de la salud han de tener en cuenta esto para la planificación y ejecución de los diferentes programas sanitarios.

Impacto a nivel de la familia

Pero el impacto del TCE no sólo se circunscribe a la pérdida de función y discapacidad en el individuo que lo sufre sino que tiene un profundo impacto sobre su entorno (Wolters Gregório et al. 2011).

Es particularmente importante cómo afecta a la familia el hecho de tener un familiar con un TCE y esta relación se ha documentado ostensiblemente en la literatura médica. El impacto del TCE sobre la familia es bidireccional. La estructura familiar y los roles dentro de la familia son susceptibles de verse alterados y consecuentemente ocasionar una situación de estrés emocional. Por otro lado, la familia puede tener un impacto negativo o positivo sobre la salud y la calidad de vida de quien padece las secuelas por un traumatismo. Un ejemplo muy obvio es el que acontece con algunos pacientes con trastornos conductuales en donde una familia que siga las pautas de los profesionales y que albergue un entorno tranquilo puede mejorar la sintomatología conductual, mientras que si el mismo paciente está en un entorno más desfavorable la sintomatología conductual puede exacerbarse(Nonterah et al. 2013).

En ocasiones, las secuelas del TCE pueden pasar desapercibidas para los profesionales ya que existe evidencia de que ciertos problemas de carácter conductual suelen manifestarse en situaciones del día a día y no durante la consulta. En circunstancias en donde la recuperación motriz es notable y hasta puede que haya alcanzado la normalidad, es posible que persistan alteraciones emocionales, conductuales, problemas cognitivos, problemas en la autoestima o hasta escasa conciencia del déficit que generen estrés y que produzcan una alteración en la dinámica familiar. No en vano es por lo que el cuidador o la familia directa del paciente que tiene un TCE tiene un riesgo elevado de padecer trastornos emocionales derivados de lo anterior(Sander et al. 2012)(Calvete & De Arroyabe 2012).

Es por esto, que las personas que han sufrido un TCE tienen más probabilidades de sufrir un divorcio además de tener un riesgo aumentado de suicidio (Skopp et al. 2012).

Curiosamente, aún a pesar de la existencia del conocimiento de estos factores, no son demasiados los estudios que evalúen el impacto del TCE sobre las familias de los afectados así como sus necesidades específicas. Lefebre (Hélène Lefebvre & Marie Josée Levert 2006; H Lefebvre et al. 2005) realizó en 2012 un estudio cualitativo en donde investigó cuales eran aquellas demandas echadas en falta por los familiares de pacientes con TCE entre las que destacaba la falta de información, soporte emocional y financiero así como también ayudas y asesoramiento sobre servicios a largo plazo.

2.3 La rehabilitación del traumatismo craneoencefálico

Section of Neurology
President-GEORGE RIDDOCH, M.D.
DISCUSSION ON REHABILITATION AFTER INJURIES TO THE
CENTRAL NERVOUS SYSTEM

Rehabilitation of the patient: after head injury.

Rehabilitation may be defined as: "The planned attempt under skilled direction by the use of all available measures to restore or improve the ***health, usefulness and happiness*** *of those who have suffered an injury, or are recovering from a disease. Its further object is to return them to the service of the community in the shortest time." Although it is a new word,* ***rehabilitation is an old purpose****.*

December 18th, 1941

Tanto en Europa como en Estados Unidos, después de la Gran Guerra y de la II Guerra Mundial aumentó el número de soldados y civiles con secuelas por TCE. Hace casi cien años el profesor Riddoch definía la rehabilitación de esas heridas como la restauración de la salud, pero entendida en un sentido amplio y similar al marco conceptual actual descrito en el modeo biopsicosocial de la enfermedad.

Este concepto de entender la salud y la enfermedad fue descrito por Engel en 1977 (Engel 1977; Imrie 2004) y en él, la salud comprende una sensación subjetiva de bienestar físico, psíquico y social que al fin y al cabo se relaciona directamente con el concepto de funcionamiento. Todas las personas, a lo largo de su vida experimentarán en mayor o menor medida una limitación en el funcionamiento, ya sea debido a una enfermedad aguda, una crónica o una circunstancia normal como puede ser el embarazo o el envejecimiento.

El objetivo último de la rehabilitación es favorecer que la persona que ha sufrido un daño cerebral tenga el mejor funcionamiento para que con ello pueda retornar a su entorno y a la comunidad.

La rehabilitación es entendida como una estrategia de salud que se inicia una vez transcurridas las fases de prevención y de tratamiento agudo y que establece unos objetivos que en términos concretos varían de paciente a paciente pero también a lo largo del tiempo (Gerold Stucki et al. 2003). Una circunstancia que se da con frecuencia en los servicios de rehabilitación es que la percepción subjetiva de mejoría que tiene un paciente no coincide con la que tiene el profesional. Esto se puede explicar por los factores personales y contextuales que hace que aun habiendo dos personas que hipotéticamente tengan la misma exploración física en términos de función y estructuras corporales, una sea dependiente de una tercera persona y la otra no. Y por tanto, la sensación de calidad de vida y de satisfacción con la calidad del servicio prestado puede variar de una a otra(H Lefebvre et al. 2005).

También hay que tener en cuenta en la rehabilitación del TCE que los déficits cognitivos interfieren con la percepción de la realidad y el paciente puede no percibir sus déficits en la medida que lo hace el profesional. Pouliquen y cols realizaron un estudio en donde el 95% de los pacientes consideraba que era capaz de volver a desempeñar su trabajo habitual, mientras que sólo un 68,3% fue considerado apto según la evaluación de los profesionales de la salud (Pouliquen et al. 2013).

El punto de partida de todo programa de rehabilitación es la definición del estado del paciente tanto a nivel *estrictamente médico*, entendiendo por ello aspectos relacionados con la homeostasis corporal, constantes, ausencia de infecciones o crisis epilépticas pero también su *estado funcional,* es decir, determinar qué grado de conciencia tiene, si se puede comunicar, si puede comer por sí mismo, si tiene capacidad de marcha o precisa ayuda por parte de terceras personas, cuál es la magnitud de esta ayuda etc…

Al determinar el grado de funcionalidad del paciente se pueden detectar aquellas áreas del funcionamiento que son precarias y entonces se pueden establecer los objetivos sobre los cuales se pueden llevar a cabo las intervenciones en rehabilitación. (Salter et al. 2011)(A. Rauch et al. 2008).

La rehabilitación como estrategia sanitaria para disminuir la discapacidad y favorecer la integración de personas con una diversidad funcionalidad es uno de los ejes de la hoja de ruta diseñada por la OMS y descrita en su informe WHO´s framework for action (WHO 2007).

A tenor de este documento, un reporte especial publicado el año pasado, la sociedad internacional de Medicina física y Rehabilitación apuntaba la necesidad de encontrar un marco conceptual común que facilitase la administración de datos relacionados con la discapacidad (T. Meyer et al. 2013). Por ejemplo, los datos de rehabilitación a menudo no se disgregan de los obtenidos en otros servicios, los servicios de rehabilitación que tienen a pacientes ingresados en los hospitales suelen recibir la compensación económica basándose en la clasificación de las enfermedades y no tanto de las secuelas y necesidades especiales que puedan requerir. Además, la rehabilitación desde un punto de vista administrativo suele tener lugar en diferentes ambientes, dependiendo de si se trata de una fase aguda, subaguda, crónica y también de las características y secuelas del paciente por lo que suelen verse involucrados diferentes profesionales (Kohler et al. 2012; von Groote et al. 2011).

Para aumentar la complejidad a la hora de diseñar programas de rehabilitación hay que tener presente la circunstancia de que la velocidad de recuperación no es la misma en todas las personas, y aunque se acepta que las mayores ganancias en rehabilitación se obtienen durante los primeros meses tras una lesión, hay una evidencia cada vez mayor de que existen personas que experimentan mejorías a largo plazo (Gray 2000)(Ulfarsson, Lundgren-Nilsson, et al. 2013).

Aquellos pacientes con lesiones severas como las situaciones de severa alteración del nivel de conciencia o que permanecen más de un día en la fase de amnesia postraumática son aquellos que tendrán secuelas y que se beneficiarán de una rehabilitación y un programa específico de rehabilitación neurológica(McElligott et al. 2011)(Sale et al. 2011)(Borg et al. 2011). Pacientes con menores secuelas pueden, según sus circunstancias, iniciar directamente un programa de rehabilitación ambulatorio.

En la elaboración de los planes de rehabilitación al igual que en otras disciplinas médicas, el uso de instrumentos de medida es necesario. La rehabilitación precisa de un o unos instrumentos que sean capaces de describir los déficits que genera el TCE y sus repercusiones funcionales. Con ello, se podrán identificar los objetivos del tratamiento y permitirá evaluar el impacto que tiene una determinada intervención sobre la funcionalidad(A. Rauch et al. 2008; Nijhuis et al. 2008; Levack 2009; McDougall & V. Wright 2009).

Otra de las características típicas en rehabilitación y que tal vez sea más notoria respecto a otras especialidades médicas (Vera Neumann et al. 2010)(Varela-Donoso et al. 2013) es la importancia y la necesidad del trabajo en equipo. La interdisciplinaridad integra a diferentes profesionales relacionados con el mundo de la salud como son médicos rehabilitadores, neurólogos, neurocirujanos, traumatólogos, fisioterapeutas, trabajadores sociales, terapeutas ocupacionales, psicólogos o logopedas, entre otros. Esta pluralidad en la evaluación tiene la misión de proporcionar una visión transversal y por tanto integral de las secuelas del paciente que garanticen posteriormente un correcto abordaje (Nancarrow et al. 2013). Sin embargo, el abordaje también incluye como se describió en los apartados anteriores, una perspectiva longitudinal teniendo en cuenta las variaciones a nivel funcional que sufren las personas con TCE a lo largo del tiempo.

Ilustración 1 Imagen del equipo interdisciplinar en el tratamiento del TCE.

Estas dos perspectivas concuerdan además con los principios de universalidad y de continuidad descritos por la Organización Mundial de la Salud en su modelo biopsicosocial. El principio de *universalidad* hace referencia a la discapacidad como fenómeno común y característico de la condición humana, y el principio de *continuidad* engloba la visión de la continua interacción de la persona, el estado de salud y el ambiente a lo largo de su vida.

Este último aspecto, refleja además la importancia de valorar la perspectiva del paciente y su propia vivencia sobre la experiencia del TCE(Epstein et al. 2005).

Los médicos rehabilitadores tienen, entre otras, la función dotar de la mejor autonomía posible a sus pacientes, pero en el paradigma de la medicina orientada al paciente típica del mundo actual en contraposición a la medicina paternalista propia de los albores de la medicina, se necesita un marco conceptual que permita asimilar la perspectiva del paciente a los programas de rehabilitación y su inclusión en los instrumentos de medida empleados en los tratamientos que han de ser lo más individualizados posibles teniendo en cuenta la idiosincrasia típica de cada persona, pero al mismo tiempo garantizando las comunalidades necesarias de un sistema de salud.

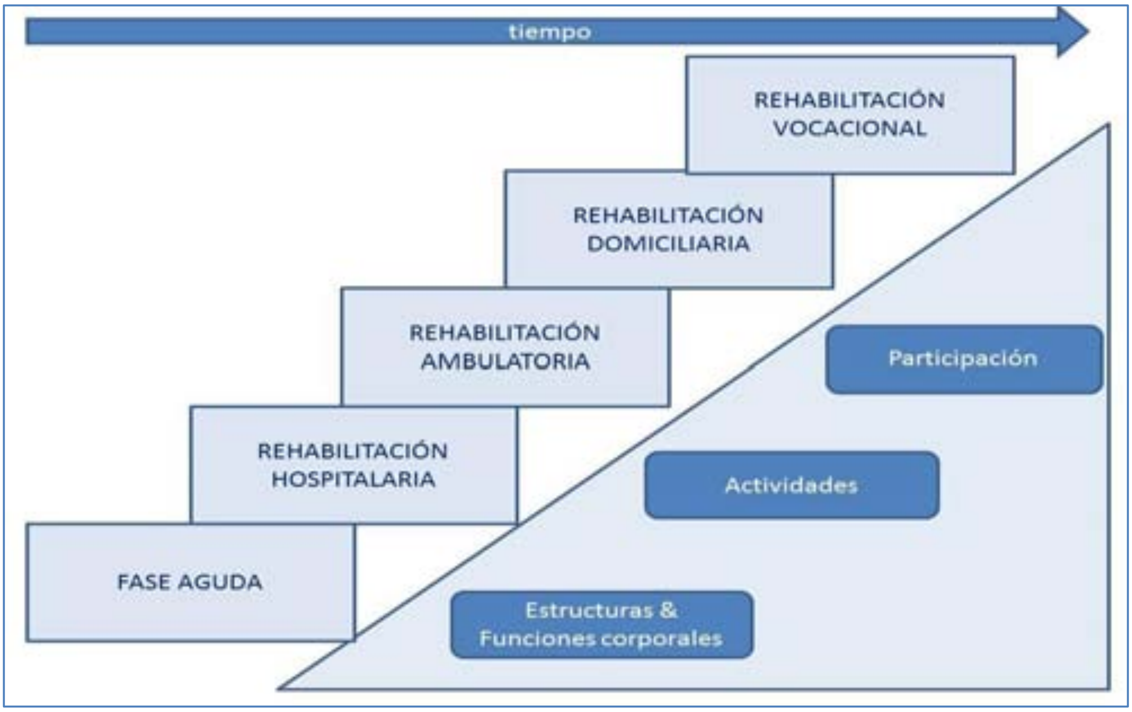


Ilustración 2 Diagrama que muestra las diferentes fases del tratamiento rehabilitador del TCE en relación a los diferentes dominios de la CIF

2.4 La clasificación internacional de la funcionalidad, discapacidad y salud

La clasificación internacional de la funcionalidad, discapacidad y salud (CIF) fue publicada por primera vez en el año 2002 por la Organización Mundial de la Salud.

Surgió como otra de las clasificaciones de la OMS dentro de la necesidad de describir mejor el espectro funcional de las personas entendiendo que la salud no sólo comprende un estado libre de enfermedad sino que comprende un estado más complejo y subjetivo influenciado por varios factores tal y como se describe en el modelo biospicosocial de Engel(Engel 1977).

Estas clasificaciones médicas tienen como objetivo facilitar el almacenamiento de datos, la búsqueda de los mismos pero también favorece su análisis e interpretación. Una buena clasificación permite comparar datos en diferentes poblaciones, en diferentes países o localizaciones pero también cambios a lo largo del tiempo.

La elaboración de clasificaciones que permiten distribuir a la población en diferentes grupos no sólo tienen un valor epidemiológico sino que pueden aportar información para tipificar el pronóstico de una enfermedad o para determinar la accesibilidad a una minusvalía. Por ejemplo, no es lo mismo padecer una esclerosis múltiple remitente recurrente o una progresiva que tener un cáncer en estadío I que III ya que la limitación en la funcionalidad cambia.

La CIF permite complementar a otras clasificaciones como son la CIE (Clasificación Internacional de la Enfermedad) o el DSM IV (Diagnostic and Statistic Manual of Mental Disorders) que tienen un enfoque predominantemente etiológico y que no contemplan las consecuencias funcionales de la enfermedad. En el contexto de mundo actual, con una mayor longevidad en la población y con una mayor supervivencia de enfermedades crónicas, el diagnóstico de las enfermedades en sí mismo no es capaz de predecir cuáles son los requerimientos de servicios hospitalarios, ni la duración de hospitalización ni el nivel de cuidados de una población. Tampoco es capaz de predecir quién se beneficiaría de ayudas a la discapacidad, ayudas en el entorno laboral tales como la disminución de barreras arquitectónicas o ajuste de horario laboral y en definitiva, la integración social.

Hasta ahora, la complejidad casuística de los pacientes ingresados en un hospital se contemplaba con el término anglosajón de "*case* mix" o grupos relacionados de diagnóstico (GRD) (Madden et al. 2013) Este concepto, surgió en los Estados Unidos hace cuatro décadas y se intentaba aplicar un sistema de pago hospitalario a través de las aseguradoras de salud fundamentado en los diagnósticos médicos capturados por la CIE. En lo que concierne al TCE, el *case mix* tal y como se entiende hoy en día, es válido para la fase aguda del TCE en donde la homeostasis corporal es fundamental y en donde se realizan intervenciones, craniectomías, traqueostomías… pero en las fases subagudas y crónicas no capturan las necesidades de la población.

Un servicio médico, por ejemplo un servicio de oftalmología, que atienda a una persona con una discapacidad es muy posible que no reciba mayores ingresos económicos aunque con toda probabilidad, la cantidad de recursos que se tengan que emplear sean significativamente más complejo que una persona sin una discapacidad.

En este sentido, el uso concomitante de la CIE y la CIF puede permitir crear una imagen más amplia y con mayor información sobre la experiencia de la salud de una población y el hecho de ser una clasificación taxonómica, la hace apta para su uso informático con un potencial de aprovechamiento importantísimo en esta era digital.

El modelo de la CIF pretende ofrecer una perspectiva integral y detallada sobre la función y la discapacidad en torno al individuo lo que permite un acercamiento a través de sus diferentes dominios para la elaboración de un perfil sobre el funcionamiento, la discapacidad y la salud de una persona. Así, se puede clasificar y describir el estado de salud de dos personas que aun teniendo la misma patología pueden tener una funcionalidad diferente, ya fuese porque están en un estadio diferente, porque tienen diferentes edades, por variaciones en la fuerza física, en la accesibilidad a recursos sanitarios, sociales, apoyo familiar…..(Alarcos Cieza et al. 2011)(Gerold Stucki et al. 2003)(A Cieza & G Stucki 2008)(Alarcos Cieza et al. 2009)

La clasificación distribuye el concepto de salud en dos bloques, por un lado el cuerpo, entendiendo éste como el conjunto de funciones y estructuras corporales, y por otro, la relación del individuo con el resto de la sociedad y el conjunto de factores que lo influyen: actividades y participación y factores contextuales.

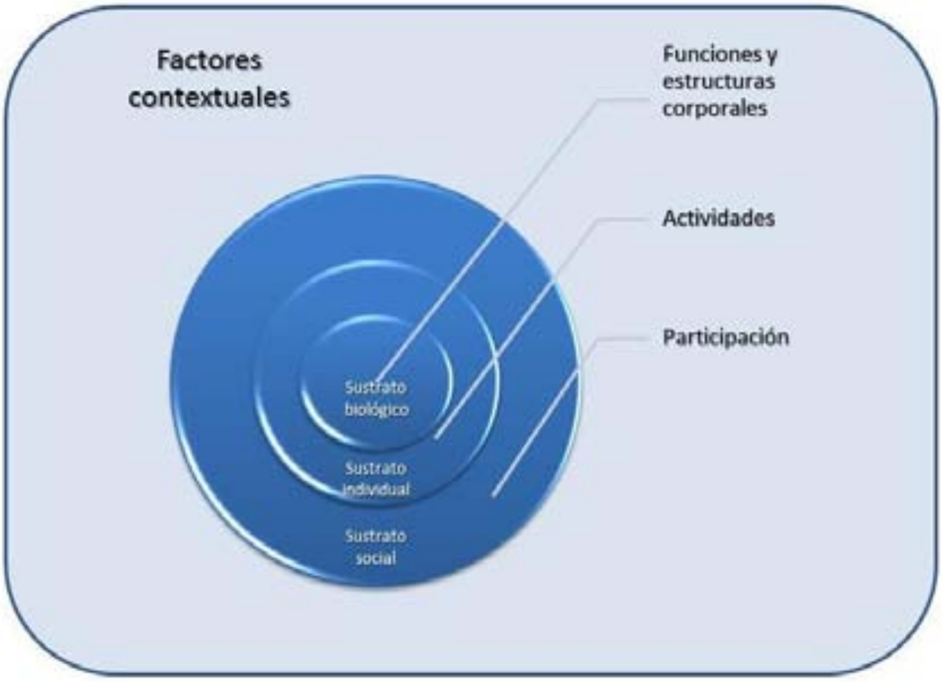


Ilustración 3 Diagrama que muestra los dominios de la CIF y su relación con el sustrato biológico, individual y social

En total, un conjunto de 1424 categorías constituyen la CIF, que está jerárquicamente organizada tal y como muestra la figura 4. Hay un total de 493 categorías dedicadas a las *funciones corporales,* 310 a *estructuras corporales,* 393 a *actividades y participación,* y 258 a *factores medioambientales.*

Las *Funciones Corporales* son aquellas funciones fisiológicas de todos los sistemas corporales en un individuo. Esta parte se divide en ocho capítulos en cada uno de los cuales se explican los dominios que son prácticos y significativos en las funciones fisiológicas como funciones mentales, habla y lenguaje y funciones neuro-músculoesqueléticas.

Las *Estructuras* son las partes anatómicas de las que se constituye un individuo y su parte se divide en ocho capítulos que se correlacionan con sus respectivas funciones corporales (funciones mentales y estructuras del sistema nervioso central).

El componente de *Actividad y Participación* detalla en realidad el estadio funcional de las personas. Los capítulos que lo constituyen se ordenan desde las tareas más sencillas a las acciones más complejas integradas en la vida de una persona como son las tareas generales, comunicación, relaciones interpersonales o vida social. Este apartado aunque está todo unificado bajo un mismo dominio, conceptualmente comprende dos ámbitos: la A*ctividad* que es la realización de una determinada tarea o acción y representa lo que la persona sería capaz de realizar en un ambiente facilitador mientras que la *Participación* es el acto de involucrarse en una situación vital y por tanto representa lo que la persona es capaz de hacer su entorno habitual.

Por último, los *Factores Ambientales* constituyen el ambiente físico, social y actitudinal en donde viven las personas y llevan a cabo su vida como son las condiciones climáticas en donde viven, las características arquitectónicas, la geografía, las actitudes sociales.... Los *Factores Personales* son los factores internos dentro de los *Factores Contextuales* y hacen referencia a la edad, el sexo, la biografía personal, nivel educativo, nivel cultural, profesión, personalidad... y dada su complejidad y variabilidad aún no han sido determinados.

Cada uno de estos apartados tiene una serie de capítulos organizados de forma jerárquica que constituyen un conjunto de códigos alfanuméricos que representan a las llamadas “categorías” . Las categorías son excluyentes entre sí pero están organizadas de tal manera que las categorías de nivel más alto (las que tienen más dígitos tras la letra) contienen atributos de la categoría inmediatamente superior. Por ejemplo, el código *b11420* representa *orientación respecto a uno mismo*, el código inmediatamente superior sería el *b 1142* sería únicamente *orientación respecto a la persona* mientras que el *b114* es *funciones de orientación*.

Además, la CIF también ofrece la posibilidad de calificar la dimensión del problema mediante puntuaciones que oscilan desde el 0 (ausencia de problema) a 4 (problema total). Mención aparte requiere el apartado de *Factores Ambientales* ya que pueden ser codificados como facilitadores (+) o barrera (-).

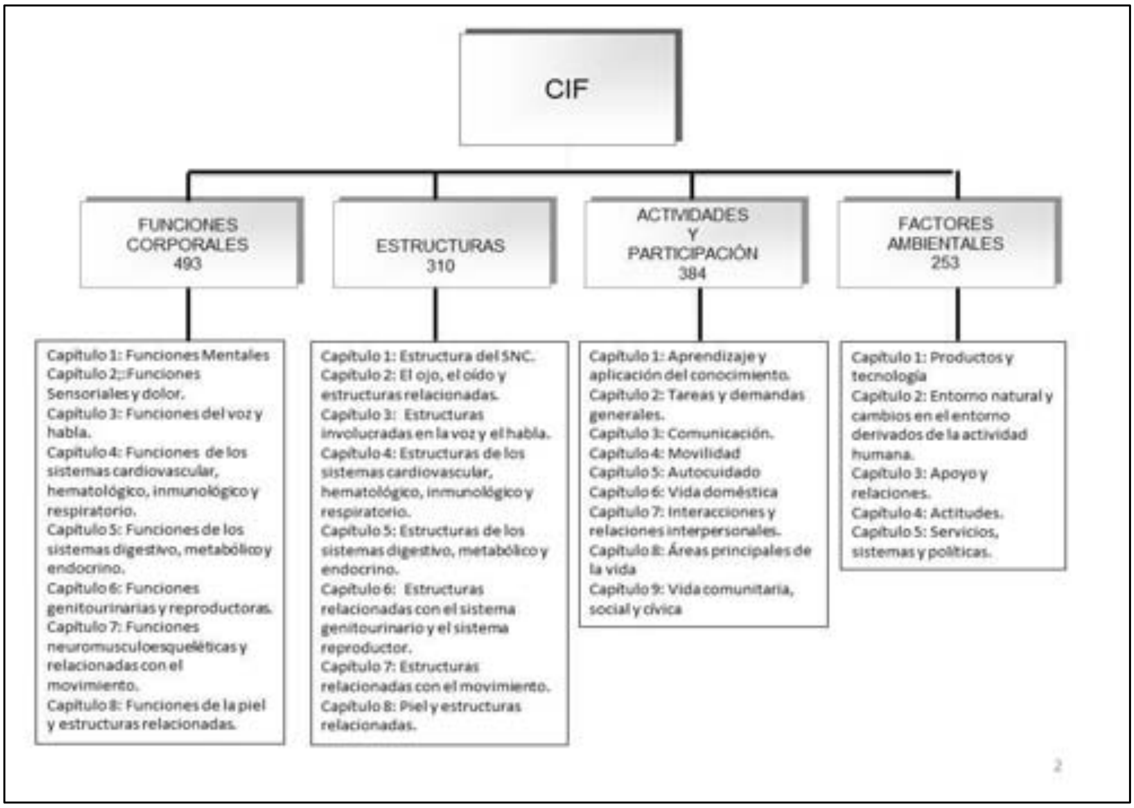
Conceptualmente la CIF diferencia y define los siguientes aspectos:

**Deficiencia*, que es la pérdida o anormalidad de una estructura, función psicológica, fisiológica o anatómica de un individuo.

**Funcionamiento* que se entiende como un término genérico que incluye las funciones y estructuras corporales, actividades y participación e indica los aspectos de la interacción del individuo con el medio (factores medioambientales).

*La *Discapacidad* es definida como la restricción o ausencia debida a la deficiencia de la capacidad para realizar una actividad considerada dentro del rango de la normalidad.

**Condición de salud* codificado según la CIE-10 como aquellas circunstancias especiales que describen el grado de salud de una persona. Este término no haría referencia únicamente a la enfermedad sino a situaciones normales como son el embarazo o el envejecimiento.



Capítulo 1: Funciones Mentales
Capítulo 2;:Funciones Sensoriales y dolor.
Capítulo 3: Funciones del voz y habla.
Capítulo 4: Funciones de los sistemas cardiovascular, hematológico, inmunológico y respiratorio.
Capítulo 5: Funciones de los sistemas digestivo, metabólico y endocrino.
Capítulo 6: Funciones genitourinarias y reproductoras.
Capítulo 7: Funciones neuromusculoesqueléticas y relacionadas con el movimiento.
Capítulo 8: Funciones de la piel y estructuras relacionadas.

Capítulo 1: Estructura del SNC.
Capítulo 2: El ojo, el oído y estructuras relacionadas.
Capítulo 3: Estructuras involucradas en la voz y el habla.
Capítulo 4: Estructuras de los sistemas cardiovascular, hematológico, inmunológico y respiratorio.
Capítulo 5: Estructuras de los sistemas digestivo, metabólico y endocrino.
Capítulo 6: Estructuras relacionadas con el sistema genitourinario y el sistema reproductor.
Capítulo 7: Estructuras relacionadas con el movimiento.
Capítulo 8: Piel y estructuras relacionadas.

Capítulo 1: Aprendizaje y aplicación del conocimiento.
Capítulo 2: Tareas y demandas generales.
Capítulo 3: Comunicación.
Capítulo 4: Movilidad
Capítulo 5: Autocuidado
Capítulo 6: Vida doméstica
Capítulo 7: Interacciones y relaciones interpersonales.
Capítulo 8: Áreas principales de la vida
Capítulo 9: Vida comunitaria, social y cívica

Capítulo 1: Productos y tecnología
Capítulo 2: Entorno natural y cambios en el entorno derivados de la actividad humana.
Capítulo 3: Apoyo y relaciones.
Capítulo 4: Actitudes.
Capítulo 5: Servicios, sistemas y políticas.

Ilustración 4 Esquema de la CIF

Sin embargo, a pesar del análisis exhaustivo del funcionamiento que hace la CIF, ha sido ampliamente criticada por su baja aplicabilidad clínica. Precisamente la amplitud y detalle de conceptos que evalúa, la hacen poco práctica tanto para su uso en la clínica diaria como para la realización de estudios e investigación.

En este sentido, la propia OMS ha promovido el desarrollo e investigación de herramientas de trabajo que facilitasen la operabilidad de la CIF.

Así surgió la ICF-Checklist 2.1a (WHO 2001 s. f.). Ésta es un conjunto de 128 categorías distribuidas en unas doce páginas que ha de cumplimentar el profesional sanitario para identificar los problemas en las áreas de funcionamiento de su paciente. Unos 32 códigos (25%) pertenecen al dominio de *funciones corporales,* 16 (13%) al dominio de *estructuras corporales,* 48 (37%) a *actividades y participación* y 32(25%) *a factores medioambientales.*

Al margen de la "checklist", también se promovió el desarrollo de los *"ICF Core Sets"* o conjunto nuclear de datos, tanto específicos para cada patología (EPOC, cáncer de mama) como para patologías que afectan a un área como patología del cuello y también existe un *Core Set* genérico para enfermedades neurológicas(Geyh et al. 2004; Alarcos Cieza et al. 2004; A Cieza et al. 2010; Coenen et al. 2011; A. Stucki et al. 2004; Brach et al. 2004; Tschiesner et al. 2010).

El desarrollo de los *ICF Core Sets* sigue dos principios. El primer proceso es la recolección de evidencia recogida mediante estudios preliminares con el fin de abarcar la mayor información posible obtenida desde diferentes perspectivas. Así se tratará de obtener qué aspectos relevantes sobre el funcionamiento describen los pacientes, los profesionales de la salud, los clínicos que están evaluando al paciente y los investigadores.

Secundariamente, la elección de las categorías que finalmente constituyen los *Core Sets*, tiene lugar mediante un proceso de votación y de consenso en donde profesionales sanitarios con expertez en la patología se reúnen procedentes de las seis regiones sanitarias de la OMS para debatir y finalmente determinar los *Core Sets*.

Los *Core Sets* tienen la misión de identificar ***qué*** hay que medir y no el ***cómo***. Esto es muy importante, porque en ningún momento tienen la intención de sustituir a instrumentos de medida ya existentes.

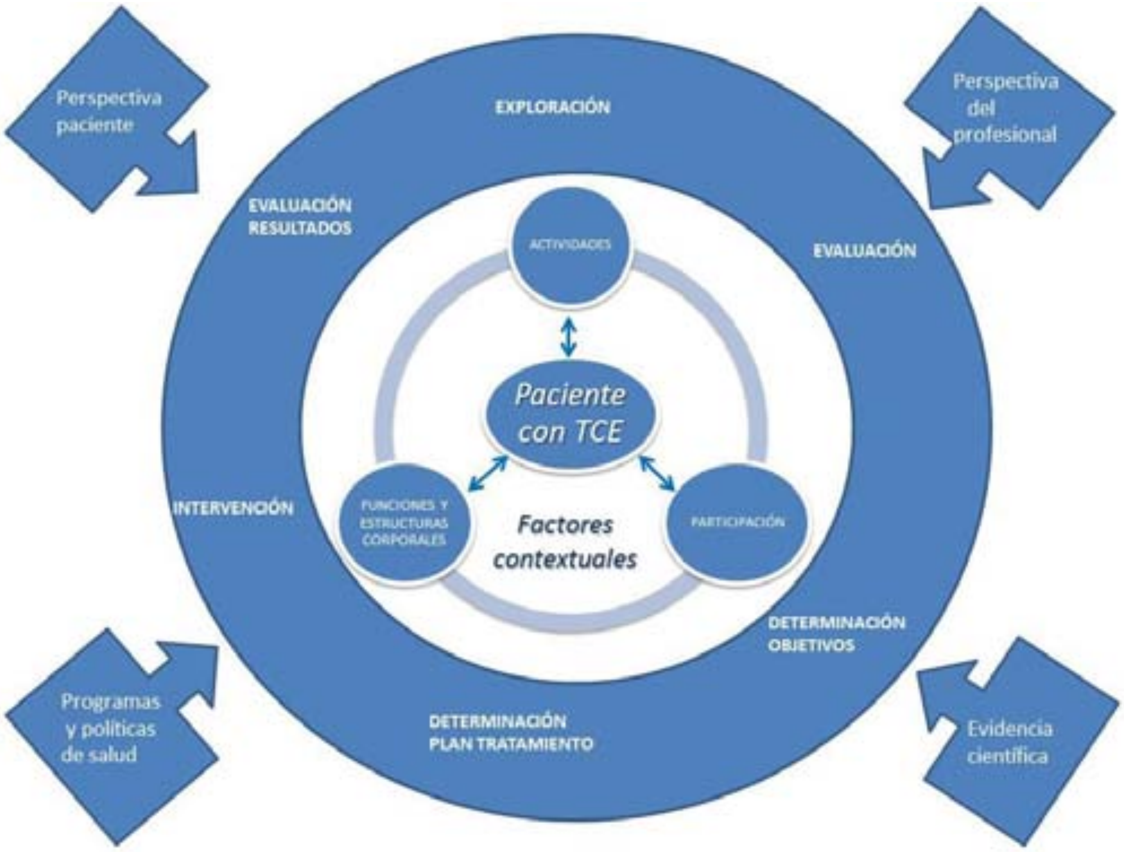


Ilustración 5 Los dominios de la CIF y su relación con las diferentes partes del tratamiento rehabilitador integrado en las perspectivas del paciente y del profesional, dentro del marco sanitario vigente y avalado por la comunidad científica.

“Linking rules”

Parte de este trabajo ha empleado la CIF como común denominador para describir el espectro funcional de pacientes con TCE, pero también para comparar los conceptos medidos en las escalas o las experiencias relatadas por los propios pacientes o los profesionales que les tratan. Para ello se empleó la metodología del *linking* o lo que se podría traducir en castellano como enlace o traducción.

Esta metodología consiste en dos pasos. El primero trata de identificar la unidad dotada de significado que mide un aspecto común. La siguiente fase consiste en identificar la categoría de la CIF que mejor defina esa unidad de significado, para lo cual debe seguir diez reglas estipuladas por Cieza (Cieza et al. 2005)(Cieza et al. 2002;).

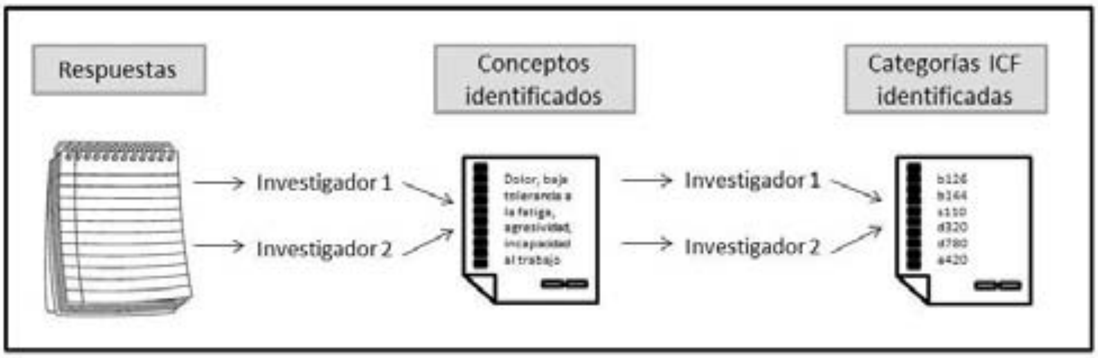


Ilustración 6 Esquema de las fases de la traducción de los conceptos a las categorías de la CIF.

3. Objetivos

El objetivo de esta tesis es la obtención de un conjunto mínimo de categorías de la CIF que faciliten la descripción taxonómica del funcionamiento de pacientes que han sufrido un TCE garantizando así el uso de un lenguaje universal e integral.

Este conjunto mínimo de datos es conocido en el mundo anglosajón como "ICF Core Sets" y su desarrollo comprende dos procesos generales.

El primero es la elaboración de un proceso basado en la evidencia, que integre la información recogida en varios estudios para capturar la información sobre el funcionamiento de paciente con TCE desde varias perspectivas: la del paciente, la del clínico, la del investigador y la del profesional de la salud.

El segundo consiste en la realización de un proceso de consenso y de selección de las categorías de la CIF aptas para la constitución de los "*ICF Core Sets"*.

Secundariamente se pretenden los siguientes objetivos:

1. Identificación de los instrumentos de medida actualmente más empleados en la rehabilitación del traumatismo craneoencefálico.
2. Análisis conceptual mediante la comparación de los diferentes dominios evaluados en los mencionados instrumentos de medida, empleando como marco conceptual la CIF.
3. Identificación de las áreas de funcionamiento alteradas en pacientes con TCE empleando la CIF con común denominador en un estudio prospectivo bajo la mirada del profesional sanitario.
4. Identificación de las áreas de funcionamiento de pacientes con TCE más afectadas, bajo la visión subjetiva de los profesionales de la salud empleando el CIF como común denominador.
5. Identificación de las áreas de funcionamiento más alteradas referidas por una población que ha sufrido un TCE tomando como marco conceptual la CIF.

6. Promoción mediante un ejercicio Delphi de la presentación de un conjunto mínimo de datos de la CIF que favorezca la interoperabilidad semántica entre los diferentes actores involucrados en el tratamiento de pacientes con TCE.

4. Presentación

Esta tesis se ha elaborado por compendio de las siguientes publicaciones:

1. ***What domains of the International Classification of Functioning, Disability and Health are covered by the most commonly used measurement instruments in traumatic brain injury research?*** Laxe S, Tschiesner U, Zasler N, López-Blazquez R, Tormos JM, Bernabeu M. Clin Neurol Neurosurg. 2012 Jul;114(6):645-50.

2. ***ICF use to identify common problems on a TBI neurorehabilitation unit in Spain***. Laxe S, Zasler N, Tschiesner U, López-Blazquez R, Tormos JM, Bernabeu M. NeuroRehabilitation. 2011;29(1):99-110.

3. ***ICF profiling of patients with traumatic brain injury: an international professional survey***. Laxe S, Zasler N, Robles V, López-Blázquez R, Tormos JM, Bernabeu M Disabil Rehabil. 2013 Apr 18.

4. ***Development of the International Classification of Functioning, Disability and Health core sets for traumatic brain injury: an International consensus process***. Laxe S, Zasler N, Selb M, Tate R, Tormos JM, Bernabeu M. Brain Inj. 2013;27(4):379-87. doi: 10.3109/02699052.2012.750757. Epub 2013 Mar 8.

ANEXO:

Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups. Sveen U, Ostensjo S, Laxe S, Soberg HL.Disabil Rehabil. 2013 May

5. Publicaciones

Clinical Neurology and Neurosurgery xxx (2012) xxx–xxx

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What domains of the International Classification of Functioning, Disability and Health are covered by the most commonly used measurement instruments in traumatic brain injury research?

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ABSTRACT

Objective: To identify the most frequently used outcome measurement instruments reported in clinical studies on TBI and to provide a content comparison in the framework of the International Classification of Functioning, Disability and Health (ICF).
Patients and methods: A systematic literature review of clinical studies in TBI was performed using Medline, EMBASE and PsychINFO. The items of the measurement instruments present in more than 20% of the studies were linked to the ICF language.
Results: 193 papers fulfilled the eligibility criteria. The frequency analysis identified six instruments: Functional Independence Measure (50%), Glasgow Outcome Scale (34%), Disability Rating Scale (32%), Wechsler Adult Intelligence Scale (29%), Trail Making Test (26%) and Community Integration Questionnaire (22%). The analysed instruments focus on different aspects of *body functions* (especially DRS, WAIS and TMT) and aspects of *activities and participation* in life (especially CIQ and FIM). Inter-researcher agreement for the ICF linking process was 0.83.
Conclusions: Translating the items of different measurement instruments into the ICF language provides a practical tool to facilitate content comparisons among different outcome measures. The comparison can assist clinical researchers to integrate information acquired from different studies and different tools.

1. Introduction

Traumatic brain injury (TBI) is a frequently occurring condition and a common cause of death and disability. Approximately 7.8 million persons live in Europe with some level of disability caused by TBI [1,2]. Impairment, activity limitations and participation restrictions are ubiquitous and very important consequences of moderate and severe TBI [3–5].

The interest in TBI rehabilitation has increased during the last decade partly as a result of the increased awareness of disability which is, for example reflected in the 2005 WHO resolution on disability, including prevention management and rehabilitation [6–8]. Rehabilitation in patients with TBI has not only a beneficial effect on improving patient quality of life, but also shortens the length of stay in acute care hospitals and diminishes other health care costs.

Measurement of physical and cognitive changes and the description of patient problems in relevant life areas are essential aspects of rehabilitation settings in order to identify, quantify and plan interventions [9,10]. The use of measurement instruments offers the clinical researcher a practical, validated and standardized way to assess the nature and degree of a person's functional disability but they can also be applied to a great variety of purposes in clinical, research, management and policy settings.

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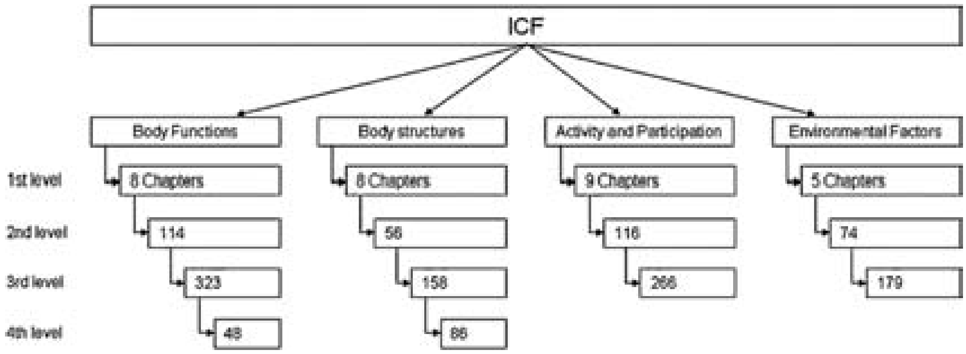

Fig. 1. Description of the ICF nested structure.

Commonly utilized TBI outcome instruments vary in scope and mode of measurement. Some instruments focus in impairments of neurological or cognitive functions whereas others focus on activity restrictions and others in the participation in society [11].

Therefore this little standardization in the use of these instruments and comparisons across studies or data from different centres and countries are difficult [12].

The World Health Organization (WHO) has adopted the International Classification of Functioning, Disability and Health (ICF) in 2001, as a universal reference framework for functioning and health. The ICF is based on a comprehensive bio-psycho-social model and has been designed as a common language for multi-professional cooperation [8,10,13–15]. The ICF is not a specific tool for assessment but a reference system that in healthcare settings reflects the findings of clinical assessments conducted by health professionals [9,16–18].

The ICF is a hierarchically organised taxonomy in a nested structure (see Fig. 1). The ICF components correspond to: *body functions* (*b*) that define physiological and psychological functions, *body structures* (*s*) that describe the anatomical parts of the body, and *activities and participation* (*d*) that comprises the full range of life areas, including the execution of a task, activities of daily life, interpersonal relationships, and community living. In addition to this, patient's functioning and disability are also influenced by contextual factors. *Environmental factors* (*e*) describe the physical, social and attitudinal environment in which people live and conduct their lives. *Personal factors* comprise individual features that are not part of the health condition, for example age, gender, race, habits, fitness or coping styles. In total, there are 1454 ICF categories, corresponding to 493 body functions, 310 body structures, 393 activities and participation and 258 environmental factors. Personal factors are not currently classified into detailed categories.

The objective of this study was to identify the most frequently used measures reported in TBI literature. A detailed content comparison to identify communalities and discrepancies of these aforementioned instruments was then made on the basis of the ICF to present their content in the neutral common framework recommended by the WHO.

2. Method

A systematic literature review was done in order to identify clinical studies on TBI. All the measures that were used in the studies were extracted and a frequency analysis was performed. For all those that were used in more than 20% of the studies, a content comparison was made on the basis of the ICF by two independent researchers [12,19–21].

2.1. Selection of studies

Three electronic databases were used for the search (Medline, EMBASE and PsycINFO) and searched for publications in the last five years using the keywords: "traumatic brain injury"; "brain injury"; "head trauma"; "outcome"; "measures"; "instrument"; "assessment"; "questionnaire"; "functioning"; "functional assessment"; "disability"; "quality of life"; and "evaluation". (The exact terms and strategies varied across databases and can be retrieved from the corresponding author.)

Studies with patients over 18 years old who fulfilled a clinical diagnosis of TBI according to the definition established by the TBI Model System were included. This covered: randomized clinical trials, controlled clinical trials, observational studies and qualitative studies were the selected study designs.

Studies with exclusively laboratory parameters, genetic studies, animal experiments, letters, comments, editorials, systematic reviews and meta-analyses were excluded. In the case of multiple publications, the paper with the highest impact factor was included. All searches were limited to articles written in English.

2.2. Identification of measurement instruments

All measurement instruments used in the studies were then identified and the number of studies was documented in which each of them was used. The instruments that were used in more than 20% of the studies were further analysed.

2.3. Linkage to ICF nomenclature

The concepts contained in the items or tasks addressed in each of the measurement instruments, were then linked to the ICF categories according to standardized linking rules by Cieza et al. [22,23]

If an item contained more than one concept or if it was specified by examples, each of them was linked separately as is shown in the following example: "*oriented: implies awareness of self and the environment. Patient able to tell you a) who he is; b) where he is; c) why he is there; d) year e) season, f) month, g) day...*" The linking would lead to *orientation* (b114), *awareness* (b1644: insight), *orientation to oneself* (b1142: orientation to person), *orientation within the environment* (b1140: orientation to place), *orientation within time* (b1141: orientation to time).

The results of the linking are presented at the second level of the classification. If a concept was linked to a 3rd- or 4th-level ICF category, the corresponding 2nd-level category was reported.

Please cite this article in press as: Laxe S, et al. What domains of the International Classification of Functioning, Disability and Health are covered by the most commonly used measurement instruments in traumatic brain injury research? Clin Neurol Neurosurg (2012), doi:10.1016/j.clineuro.2011.12.038

Table 1
Representation of the 20 most frequent measurement instruments identified. The other 263 instruments have a frequency of less than 5%.

Measurement instrument	Occurrence frequency
Functional Independence Measure	50%
Glasgow Outcome Scale	34%
Disability Rating Scale	32%
Wechsler Adult Intelligence Scale III	29%
Trail Making Test (A & B)	26%
Community Integration Questionnaire	22%
Wisconsin Card Sorting Test	15%
Barthel Index	14%
Controlled Oral Word Association Test	14%
Galveston Orientation and Amnesia Test	13%
California Verbal Learning Test	12%
Rancho Los Amigos Level of Cognitive Functional Scale	12%
Mini Mental State Examination	10%
Stroop Color Word Test	10%
Beck Depression Inventory	9%
Functional Assessment Measure	9%
SF-36	8%
Sickness Impact Profile	7%

2.4. *Interrater reliability*

All steps of the review were done by two health professionals (SL, physician with specialization in PM&R and RL, statistician) who were trained at the ICF Research Branch, WHO FIC Collaborating Center at the Ludwig Maximilian University in Munich.

The degree of agreement between the two health professionals was calculated by means of the kappa statistic. The values of kappa generally range from 0 to 1, in which 1 means perfect agreement.

3. Results

The electronic search identified 1089 articles. An abstract check yielded 274 articles which were fully read. Finally, 193 articles fulfilled the eligibility criteria.

Two hundred eighty three (283) different instruments were identified in the studies. Out of these, six instruments were used in more than 20% of the studies and their content were linked to the ICF. Functional Independence Measure (FIM, 50%), Glasgow Outcome Scale (GOS, 34%), Disability Rating Scale (DRS, 32%), Wechsler Adult Intelligence Scale (WAIS, 29%), Trail Making Test (TMT 26%) and Community Integration Questionnaire (CIQ, 22%). The Glasgow Coma Scale was found to be named in the papers in a 33% but [24] is not truly an outcome measure as it measures impairment. It can be used as an outcome measure in a very acute phase to measure the effects of a treatment or neurosurgery but basically defines the severity of the TBI [25] (see Table 1).

The Functional Independence Measure (FIM) is an 18 item scale assessing different aspects of independent performance in life areas such as feeding, grooming, toileting, self-care, transfers, locomotion, as well as cognitive items for communication, memory, problem solving and social interaction [26]. The advantage of this tool is that it has shown the ability to detect changes in a rehabilitation setting but the usefulness is limited by a ceiling effect after discharge [27].

The Glasgow Outcome Scale (GOS) is the widest method for classifying outcome in TBI patients. It includes 5 items and is a brief descriptive outcome scale to describe a general assessment of functioning. It is used more frequently in clinical practice than an extended interview version of the GOS that has been reported recently [28].

The Disability Rating Scale (DRS) is a 30 point measure consisting of eight items assessing different areas of functioning such as eye opening, verbalization, feeding, toileting and grooming, dependence on others and employability [29]. It was originally developed to assess individuals with TBI during the recovery phase. However, there are some recommendations towards the use of the GOS in controlled trial setting [30].

The Community Integration Questionnaire (CIQ) is a 15 item sale designed to measure return to social and community life after TBI and it is most appropriate to quantify TBI outcome at participatory (handicap) level [31].

Cognitive deficits are often overlooked as outcome tools for TBI patients, but studies have shown that tests of orientation, verbal memory and processing speed are the most consistent predictors from a neuropsychological assessment [32].

The Trail Making Test (TMT) is a neuropsychological test with two parts to provide information on visual attention, scanning, speed of processing, mental flexibility and performance [33]. The Wechsler Adult Intelligence Scale (WAIS) consists of a battery of tests that examines cognitive abilities, both verbal and visual-spatial [34–36]

Table 2a
Content comparison of outcome measures based on the ICF linking for body functions ($n = 20$).

ICF code	Explanation	CIQ	DRS	FIM	GOS	TMT (A&B)	WAIS	Total
b110	Consciousness functions		xxx		x			2
b114	Orientation functions		xxx					1
b117	Intellectual functions				x			1
b126	Temperament and personality functions	x						1
b140	Attention functions		x			x		2
b144	Memory functions			x				1
b156	Perceptual functions		x					1
b160	Thought functions						x	1
b164	High level cognitive functions	x	xxx			x	x	4
b215	Functions of structures adjoining the eye		xxx					1
b280	Sensation of pain		xxx					1
b310	Voice functions		x					1
b320	Articulation functions		x					1
b330	Fluency and rhythm of speech functions		x					1
b510	Ingestion functions			xxx				1
b525	Defecation functions			x				1
b730	Muscle power functions		x					1
b750	Motor reflex functions		x					1
b755	Involuntary movement reaction functions		x					1
b760	Control of voluntary movement functions		x					1
Total		2	14	3	2	2	2	

x: 1 or 2 items included, xxx: 3 or more items included.

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Table 2b
Content comparison of outcome measures based on the ICF linking for activities and participation ($n = 36$).

ICF code	Explanation	CIQ	DRS	FIM	GOS	TMT (A&B)	WAIS	Total
d1	Learning and applying knowledge			x				1
d175	Solving problems			x				1
d310	Communicating with receiving spoken messages		x	x				2
d315	Communicating with receiving nonverbal messages		x	x				2
d330	Speaking		x	x				2
d335	Producing nonverbalmessages			x				1
d410	Changing basic body position			xxx				1
d420	Transferring oneself			xxx				1
d450	Walking			x				1
d455	Moving around			xxx				1
d465	Moving around using equipment			x				1
d470	Using transportation	x						1
d510	Washing oneself		x	x				2
d520	Caring for body parts		xxx	xxx				2
d530	Toileting		x	x x				1
d540	Dressing			x x				0
d550	Eating		x	xxx				2
d560	Drinking		x	xxx				2
d598	Self-care		x					1
d620	Acquisition of goods and services	xxx		x				2
d630	Preparing meals	x						1
d640	Doing housework	x						1
d660	Assisting others	x						1
d710	Basic interpersonal interactions			x				1
d750	Informal social relationships	x						1
d760	Family relationships	x						1
d825	Vocational training	x			x			2
d830	Higher education	x			x			2
d840	Apprenticeship	x						1
d845	Acquiring, keeping and terminating a job	x			x			2
d850	Remunerative employment	xxx	xxx		x			3
d860	Basic economic transactions	x						1
d865	Complex economic transactions	x						1
d870	Economic self-sufficiency	x						1
d910	Community life	x			x			2
d920	Recreation and leisure	x						1
Total		17	10	17	5	0	0	

x: 1 or 2 items included, xxx: 3 or more items included.

3.1. Linkage to ICF nomenclature

The items of the six identified instruments were linked to 212 different ICF categories.

Tables 2a–2c summarize the 2nd level ICF categories that were covered by the different instruments.

The majority of the concepts referred to activities and participation ($n = 154$, 73%). Another 51 concepts were linked to the component *body functions* (24%), and only 3% were related to contextual *environmental factors*. No items in the instruments were linked to the assessment of *body structures*.

As expected, the identified measurement instruments focus on different aspects of rehabilitation after TBI: FIM and the CIQ focus predominantly on *activities and participation* in life; whereas, the other instruments put relatively stronger emphasize on the assessment *body functions*.

TMT and WAIS are neuropsychological tests and are confined to the assessment of attention, thought and cognitive functions (b140, b160, b164). However, they do not directly cover activities in life such as learning, applying knowledge and solving problems (d1, d175).

CIQ is a measure for social integration and covers activities and participation in life that are more closely connected to social integration, but not other aspects of functioning and disability.

DRS and FIM assess functional outcome with a wider focus to guide the rehabilitation process. They are the only instruments to cover speaking (b310–b330, d310–d335), food intake (b510–b525, d550–d560) and self-care (d520–d540). While the DRS is the only instrument to cover pain (b280), the FIM is the only one to cover patient mobility (d410–d465).

3.2. Interrater reliability

The results of the kappa statistic showed a 0.83 index of agreement for both reviewers with a bootstrapped confidence interval at the second level categories between 0.77 and 0.83.

4. Discussion

This study provides a content comparison among outcome measurement instruments in TBI. With the help of the ICF classification as a reference and the ICF linking rules as a practical guideline, the items in the different instruments were translated into a universal and neutral language on functioning and disability. As the statement made by Scarponi et al. [39], the ICF is a flexible instrument for monitoring outcome and defining goals for rehabilitation. Therefore, this study not only provided new insights into the nature of the included instruments, but also provided TBI researchers with a new procedure to facilitate content comparisons among outcome measurement instruments. The ICF adequately covered the items of the instruments and should therefore a useful frame of reference in the care and rehabilitation of patients with TBI. Similar experiences with the linkage of instruments to the ICF have been reported in other conditions such a stroke [11,16,21].

A systematic literature review identified instruments that had been frequently applied and published. The analysed instruments

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Table 2c
Content comparison of outcome measures based on the ICF linking for contextual environmental factors that influence the rehabilitation process ($n = 4$).

ICF code	Explanation	CIQ	DRS	FIM	GOS	TMT (A&B)	WAIS	Total
e115	Products and technology for personal use in daily living		x					1
e120	Products and technology for personal indoor and outdoor mobility and transportation		x					1
e320	Friends	x						1
e340	Personal care providers and personal assistants		xxx					1
Total		1	3	0	0	0	0	

x: 1 or 2 items included, xxx: 3 or more items included.

match up with those recommended by different groups to be used in clinical trials for TBI [24,25,37,38]. The linking of the items in the instruments into the ICF gave us more detailed insights into the content covered by each of the instruments. Most of them were related to the measurement of cognitive impairment and the ability to perform activities rather than addressing functioning from a comprehensive rehabilitation perspective.

Most of the items in the instruments were related to the ICF component of *Activities and Participation*, these findings were consistent with the study of Koskinen et al. [11]. The interest in rehabilitation for this domain of the ICF relies on the fact that activities and participation are the areas in which the rehabilitation team can sustain the efforts for treatment [40–42]. The analysed instruments cover key issues such as impairments in solving problems, applying knowledge, communication, mobility, self-care and major life areas were covered but they differed in the subcategory coverage and their approach to assess their activity and participation status. Domains 4 (mobility) and 5 (self-care) were covered in great detail; especially, the categories d410 *changing basic body position* ($n = 14$), d420 *transferring oneself* ($n = 8$), d510 *washing oneself* ($n = 11$), d520 *caring for body parts* ($n = 12$), d530 *toileting* ($n = 13$), d540 *dressing* ($n = 12$). The majority of these concepts were covered by the FIM in third and fourth levels indicating a greater specification of the items measured. While the FIM covers many aspects of communication (d3), mobility (d4) and self care (d5), the CIQ is focused on domestic life (d6), interpersonal interactions and relationships (d7), work, employment and economic life (d8) and community, recreational aspects of life (d9).

The majority of ICF categories on *Body functions* relate to domain 1 (mental functions) and domain 7 (neuromusculoskeletal and movement related functions). The content comparison of the scales showed that the areas covered by the instruments have little overlap. The category b164 *higher level cognitive functions* was the only ICF category that was represented in four instruments, while all others were represented in just one or two of the selected instruments.

Within *body functions*, cardiovascular, haematological, immunological, respiratory, metabolic, endocrine and genitourinary functions were not addressed in the selected instruments on TBI, as expected. This is especially interesting for genitourinary functions, because – from a clinical perspective – incontinence and reproductive problems are relevant problems in the rehabilitation process. The category d530 (toileting) and its subcategories d5300 (regulating urination) and d5301 (regulating defection) are addressed in the FIM indirectly referring to genitourinary functions. The aforementioned categories are related to the movement functions regarding coordinating and managing urination such as indicating the need to use the restroom, getting into the proper position and manipulating clothing than the function itself (incontinence, urge, reflux, etc.).

Aspects of contextual *environmental factors*, that may also influence the rehabilitation process, are only covered in a limited number of items and only by 2/6 of the analysed instruments: CIQ and DRS. However, in the development of the ICF Core Sets for other neurological conditions such as stroke, this component was widely represented [43].

Even though environmental factors cannot qualify as an outcome measure, its implication as barriers of facilitators can indeed affect the overall outcome. Previous studies named some environmental factors such as the use of drugs, walking aids, family support, social security systems and health care as factors influencing the overall outcome of patients in a specific health condition [44–46]. Through the application of the ICF and this linking procedure, it was possible to study the heterogeneity of the most frequently applied instruments in TBI clinical trials. Studies like this provide a useful tool to gather more detailed information on the instruments and to prevent research gaps or major redundancies in the data collection process. Nevertheless such studies can never substitute for individual and thorough study of the instruments before selecting the appropriate instrument.

The ICF offers a framework for a comprehensive understanding of the aforementioned components of health and is being increasingly used in clinical practice as well as research. It focuses on "what" to measure and not "how" to measure. The ICF and instruments attempting to operationalize the ICF such as the core sets do not and will not substitute for any of the currently utilized measures [19]. Instead they provide a useful tool to determine "what" is being measured within the currently available instruments. ICF core sets aim to help in selecting which is the best instrument for a specific purpose. Furthermore ICF Core Sets will help in designing new measuring instruments to address aspects of the individual with a particular pathology that have not been previously addressed (e.g., the lack of focus on environmental factors within the currently available measuring instruments) [47].

5. Conclusions

There is no universally accepted outcome measurement instrument that incorporates the full spectrum of problems in functioning that are associated with TBI. The assessment of the patient's problems is of vital importance for planning intervention management, outcome evaluation and service provision. Within this study it was demonstrated that the ICF can be used to differentiate the different aspects of rehabilitation that are included in the most common measurement instruments used in TBI trials. The monitorization of outcomes can help clinicians to understand better the effectiveness of an intervention and to compare the results from different studies that used different measures. The use of a common language such as the ICF can be of help to different professionals to integrate information coming from different tools. Further work towards a development of a specific TBI ICF Core Set is needed. The ICF Core Sets for TBI are to be developed through a decision making process that integrates evidence from different studies conducted to capture the health professional perspective, the patients perspective, the clinical perspective and the researcher's perspective. The data gathered from this study aims to provide information from

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the researcher's perspective during the consensus conference for the development of the ICF Core Sets for TBI.

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ICF use to identify common problems on a TBI neurorehabilitation unit in Spain

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Abstract. *Objective:* To describe functioning and health of individuals with traumatic brain injury (TBI) based on the International Classification of Functioning, Disability and Health (ICF).

Methods: A cross-sectional, prospective study was conducted in a neurorehabilitation hospital. Data collection included socio-demographic factors, single interviews based on the extended ICF Checklist 2.1 for TBI, patient ratings on general health and functioning status, WHOQoL, EQ5D and the Comorbidity Questionnaire.

Results: 103 patients (81%males) were included in the study. The mean of age was 34 yrs. 24% were inpatients whereas 76% were outpatients.

130 out of 150 categories (87%) of the extended checklist were relevant in $>$ 10% of patients. Differences in functioning and disability between patients in the shorter versus long term situation were noted to be predominantly in the ICF domains of *Activities and Participation* as well as in *Body Function*s. Correlations between EQ5D and ICF-based data collections were all $p < 0.01$.

Conclusions: This study identified the most common problems in patients with TBI receiving Neurorehabilitation services based on the ICF. Results emphasize the need to describe disability and rehabilitation standards from a comprehensive perspective that not only includes *Body Functions and Structures* but also the ICF domains of *Activities and Participation* and *Environmental factors.*

Keywords: Traumatic brain injury, disability, International Classification of Functioning, Disability and Health (ICF), multi-centre study

1. Introduction

Traumatic brain injury (TBI) is the most common cause of disability and death among young people [15]. Approximately 7.8 million people in Europe and 5.3 million in the USA live with some level of disability caused by TBI [23,33]. Traffic accidents are the leading cause for TBI, according to a report from World Health Organisation (WHO), "The global burden of disease" [40] road traffic accidents are expected to rise from a 9th to a 3rd position by year 2030 and consequently, the prevalence of TBI will likely increase in the future.

Making a medical diagnosis of TBI is not sufficient in terms of describing the health status of a patient with TBI sequelae. TBI can affect body structures and functions and these may lead to activity limitations and participation restrictions. These include not only headaches and cognitive impairments, but also irritability, anxiety and depression, as well as everyday problems with changing and maintaining body position, handling objects, walking, moving around and using public transportations, interpersonal interactions and relationships, as well as occupational and recreational activities. As a consequence, the overall quality of life of persons with TBI is negatively affected [16].

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There is no universally accepted overall outcome measure that incorporates the full spectrum of functional impairments and quality of life problems that are associated with TBI, although there is an extensive literature on outcome measures that have been used in clinical studies and evaluation of TBI (some of which have been developed for other disorders or for general health outcomes and adapted for TBI). There is no clear consensus on which measure or measures is/are the most appropriate for defining particular aspects of outcome. Professionals working in the field of traumatic brain injury normally use a range of measures to describe physical, cognitive and behavioural capacities but there is a lack in performance assessment influenced by environmental and personal factors. An important basis for the optimal management of TBI is an in-depth understanding, systematic consideration and sound measurement of the impact of the injury on health and health-related domains [22].

The International Classification of Functioning, Disability and Health (ICF) has been adopted by the World Health Organization [41] to comprehensively describe limitations in functioning and relevant contextual environmental factors. The ICF offers a framework for a comprehensive understanding of the components of health. From a clinical perspective, ICF provides a common language for health professionals with different backgrounds. Typically, rehabilitation settings, specially those related to TBI, are based on a multidisciplinary approach through a multidisciplinary team; therefore, there is a need to use a common language to describe the patient's problems. From a research perspective,the ICF may be considered as standard framework to describe functioning, to analyze the conceptual basis of current outcome measures,and to compare data from different clinical studies and centers. Additionally, from a health care policy perspective, the ICF makes it possible to link data across conditions or interventions for efficient, transparent, and cost-effective health care management [12].

The ICF is based on a bio-psycho-social model and therefore its categories are divided into the components of *"body functions"*, *"body structures"*, *"activities and participation"* and contextual *"environmental factors"*. *Body functions* are the physiological and psychological functions of the body system. The categories all start with the letter "b" followed by a numeric code. *Body structures* refer to the anatomical parts of the body.The categories all start with the letter "s" followed again by a numeric code. *Actitivities and participation* cover a full range of life activities and involvement in life situations and its categories all start with the letter "d". The categories in *Environmental factors* ("e") describe the physical, social and attitudinal environment in which people live and conduct their lives.

Altogether the ICF classification covers 1454 different and hierarchically organized categories. To increase clinical applicability of such a comprehensive classification, practical tools such as the ICF checklist have been developed [42]. In the field of TBI, only a limited number of clinical studies have been based on the ICF [1,2,4,23,24,26,28,30,33].

In order to further increase clinical applicability of the ICF, ICF "Core Sets" have been developed for 16 burdensome diseases [5,6,11,14,19,29,34,37]-not including TBI. ICF Core Sets are a pre-selection of ICF categories that are clinically relevant to a multidisciplinary team and a given disease. This study is also part of the development process for ICF Core Sets for TBI [3].

The aim of the present study was to describe functioning and disability in patients with TBI within ICF's bio-psycho-social model. Frequencies and intensity ratings were collected for all ICF categories of the extended ICF checklist for TBI.

2. Methods

This was a cross-sectional study conducted in a neurorehabilitation hospital and was designed according to the the ethical principles of the Declaration of Helsinki. The study was approved by the local ethics committee.

2.1. Participants

Patients were subsequently enrolled at the hospital for Neurorehabilitation and recruited if they met the following inclusion criteria: (1) Diagnosis of TBI according to the diagnostic criteria of the TBI Model System, (2) Patients 18 years and older. (3) Informed consent of the patient or (in the case that they were not able to consent) their proxy. (4) Absence of other comorbidity that could have affected the biopsychosocial condition.

2.2. Measures

Data collection included sociodemographic and other data regarding the injury: date and course of injury, Glasgow Coma Scale (GCS) [35] at the time of injury, Level of Cognitive Functioning Scale at time of interview, duration of postraumatic amnesia (PTA) as measured by the Galveston Orientation and Amnesia Test (GOAT) [25] and aetiology.

For the assessment of the subjective appraisal of health and well-being, the World Health Organization Quality of Life Questionnaire (WHOQoL) [8] and the EQ- 5D were used as well as the self-administered Comorbidity Questionnaire (SCQ) [32].

The basis for the extended ICF Checklist for TBI was the general ICF checklist version 2.1 developed by WHO that includes 123 ICF categories out of the entire ICF classification system [42]. Twenty seven additional categories were added to develop an extended checklist specific for TBI. These additional categories were identified through a content comparison of measurement instruments based on established linking-rules [13]. Altogether the extended ICF checklist for TBI included 150 ICF categories [1]. The level of impairment or restriction due to TBI for each category was qualified as suggested by the WHO [41]: 0 = no impairment; 1 = mild problem (5–24%); 2 = moderate problem (25–49%); 3 = severe problem (50–95%) and 4 = complete problem (96–100%). In addition, there was an option 8 = not specified, (i.e. the available information cannot sufficiently quantify the severity of the problem) and an option 9 = not applicable to this patient (for example, b650, menstruation functions in male patients).In the environmental factors, the barriers or facilitators were also reported with a (-) or (+) respectively.

Within the scope of this study, the problems that were associated with non-TBI health conditions were assigned option C (for comorbidity) and the magnitude of the problem quantified. Also there were open questions asking for additional health areas that were relevant to the patient but not covered by the extended ICF checklist for TBI.

Patient recruitment and data collection including the ICF interviews were performed by a medical doctor trained in ICF methodology and interviewing techniques through a two day workshop by researchers of the WHO ICF Collaborating Centre from the University of Munich.

2.3. *Statistical analyses*

Descriptive statistics were used to characterize the study population and to examine the frequency of problems recorded with the extended TBI ICF checklist. ICF categories in the components of "*body functions*", "*body structures*" and "*activities and participation*" were reported in percentages according to the degree of impariment (0,1,2,3 or 4) as were the percentage of patients with any degree of impairment (sum of 1–4). For "*environmental factors*" absolute frequencies of responses by persons with TBI were reported as either a "barrier" or "facilitator".

2.3.1. *Correlation of answers from EQ5D with extended ICF checklist*

The items in the EQ5D were translated according to pre-defined linking rules in a standardized procedure [9, 13,36]. Pearson correlation coeficients were calculated with an assumed level of significance of $p < 0.05$.

2.3.2. *Comparison between in-patients versus out-patients*

A comparison of in-patients versus out-patients was taken as an approximate to differentiate between patients with a shorter versus a longer time of recovery and rehabilitation after the brain injury. Statistically significant differences between the two subgroups of patients (in-patients vs. out-patients) were calculated with the Mann-Whitney-U-Test. Data entry and analyses were performed with SPSS for windows.

3. Results

From September 2008 to September 2009, 103 patients (83 male, 20 female) with a mean age of 34 years (range: 12–78 years) were recruited to participate.

The mean Glasgow Coma Scale (GCS) score was 5.3 (SD 2.4) and the average Level of Cognitive Functioning Scale (LCFS) at the time of the interview was 7.2 (SD 1.4). The average time since TBI for all patients in the study was 60 months. Additional demographic and disease-related data are summarized in Table 1.

Out of all 103 patients, 78 patients (76%) were out-patients with an average time since TBI of 77 months (range 3–339 months) and 25 patients (24%) were in-patients with an average time since TBI of 5 months (range 1–10 months). While the two groups did not show significant differences in terms of age, gender and initial GCS, there were significant differences according to the time since TBI, the LCFS at the interview, the assessment of general health and an overall level of functioning at the time of the interview (Table 2). The self administered Comorbidity Questionnaire revealed a relatively good state of health. Twenty five patients (24%) reported back pain. There were no significant differences between the in-patient and the out-patient group.

Table 1
Socio-demographic and clinical characteristics of the patients ($n = 103$)

	Number of patient (percentage)
Age (years)	34 (range: 12–78)
Gender, male:female ratio	83:20 (81:19)
Marital status	
Single, never married	72 (70)
Married	19 (18)
Cohabitating	6 (6)
Separated, divorced	4(4)
Unknown	2 (2)
Living status	
With family/spouse	102 (99)
Alone	1 (1)
Education	
Years of education	11.3, SD 3.6
Occupation	
Paid employment	15 (15)
Unemployed due to TBI	60 (58)
Unemployed for other reason	6 (6)
House	3 (3)
Student	8 (8)
other	9 (9)
Etiology	
Traffic	84 (81)
Sports	4(4)
Fall	10 (10)
Others	5 (5)

Table 2
Comparison of Patient groups (in-patient versus out-patient)

	Inpatient ($n = 25$)	Outpatient ($n = 78$)	p-value
Age (yrs)	38	33	0.214 ns
Gender (male: female)	21:4	62:16	0.621 ns
GCS (at injury)	4.96	5.44	0.411 ns
Time since TBI (months)	5	77	0.000**
CFS (at interview)	6.28	7.44	0.001**
General health	3	1	0.000**
Overall functioning	1	6	0.001**

*P-value < 0.05 significant, (ns): not significant with $p > 0.05$ with Mann-Whitney-U Test.

The EQ5D includes 5 domains for mobility, self-care, usual activities, pain and anxiety. All domains reported some level of problem in TBI patients with significant differences between the in-patients and out-patients for mobility, self-care and usual activities (Table 3).

The WHOQoL showed that the majority of the patients in both groups (in-patient and out-patient) had a lack of satisfaction with their ability to perform daily living activities. Significant differences were found between the two groups: The in-patient group reported higher levels of dissatisfaction with their overall quality of life, health, ability to perform daily activities and with their living conditions (Table 4).

Detailed analyses of patient functioning with the extended ICF checklist for TBI identified that 130 out of 150 categories (87%) are problematic/relevant to at least 10 percent of the patients. Thirty four out of forty one categories from *body functions* (80%) were reported as problematic in more than 10% of the patients. Out of these, 7 ICF categories were reported as problematic in greater than 80% of the patients. All these categories are in the chapter on mental functions (b1) including high level and *intellectual functions* (*b117*), *energy and drive functions* (*b 130*), *temperament and emotional functions* (*b126*), *muscle functions* (*b730*), *perceptual functions* (*b156*), *muscle tone functions* (*b735*) *and mobility of joint functions* (*b710*) (Table 5).

For categories referring to *body structures*, 7 of the 16 ICF categories (44%) were impaired in more than 10% of the patients. "*Structure of the brain*" (s110) was impaired in 96% of all patients (Table 6).

Table 3
EQ5D

EQ5D	Inpatient	Outpatient	Total	p-value
*Mobility**				0.005**
I have no problems in walking out	16	37.2	32	
I have some problems in walking out	56	56.4	56.3	
I am confined to bed	28	6.4	11.7	
*Self care**				0.000**
I have no problems with self care	8	46.2	36.9	
I have some problems washing or dressing myself	60	42.3	46.6	
I am unable to wash or dress myself	32	11.5	16.5	
*Usual activities**				0.003**
I have no problems with performing my casual activities	8	19.2	16.5	
I have some problems with performing my usual activities	28	52.6	46.6	
I am unable to perform my usual activities	64	28.2	36.9	
Pain				0.325 (n.s.)
I have no pain or discomfort	44	55.1	52.4	
I have moderate pain or discomfort	52	42.3	44.7	
I have extreme pain or discomfort	4	2.6	2.9	
Anxiety				0.358 (n.s.)
I am not anxious or depressed	36	44.9	42.7	
I am moderately anxious or depressed	48	44.9	45.6	
I am extremely anxious or depressed	16	10.3	11.7	

Results are reported in absolute frequencies in percentages.
Comparison of Patient groups (in-patient versus out-patient) with Mann-Whitney-U Test;
**level of significance $p < 0.001$;
n.s. not significant.

Table 4
WHOQoL

WHO QoL		VD	D	N/S	S	VS	p-value
How satisfied are you with the quality of your life?*							0.001**
	Inpatient	28	32	20	16	4	
	Outpatient	7.7	11.5	4.1	30.8	9	
	Total	12.6	16.5	35.9	27.2	7.8	
How satisfied are you with your health?*							0.001**
	Inpatient	16	28	36	16	4	
	Outpatient	3.8	11.5	34.6	23.1	26.9	
	Total	6.8	15.5	35	21.4	21.4	
How satisfied are you with your ability to perform your daily living activities?							0.047*
	Inpatient	40	24	20	12	4	
	Outpatient	16.7	26.9	37.2	11.5	7.7	
	Total	22.3	26.2	33	11.7	6.8	
How satisfied are you with your personal relationships?							0.662 (n.s.)
	Inpatient	8	16	36	12	28	
	Outpatient	9	16.7	33.3	25.6	15.4	
	Total	8.7	16.5	34	22.3	18.4	
How satisfied are you with the conditions of your living place?*							0.003*
	Inpatient	8	28	28	12	24	
	Outpatient	3.8	2.6	24.4	28.2	41	
	Total	4.9	8.7	25.2	24.3	36.9	

Results are reported in absolute frequencies in percentages.
Comparison of Patient groups (in-patient versus out-patient) with Mann-Whitney-U Test.
VD: very dissatisfied, D:dissatisfied. N/S: neither satisfied or dissatisfied. S: Satisfied. VS. Very satisfied.
**level of significance $p < 0.001$;
*level of significance $p < 0.05$;
n.s. not significant.

Table 5
ICF-catgories in *Body Functions* from the Extended ICF checklist for TBI. Proportional distribution of patient answers (%)

ICF category	ICF title	0	sum 1–4	1, mild	2, moderate	3, severe	4, complete	8, not specified	9, not applicable
b110	Consciousness functions	85	15	5	4	2	4		
b114*	Orientation functions	60	40	16	5	7	13		
b117*	Intellectual functions	13	87	21	24	20	21		
b126*	Temperament and personality functions	14	86	17	23	18	27		
b130*	Energy and drive functions	13	87	7	7	7	67		
b134	Sleep functions	72	28	14	11	2	2		
b140*	Attention functons	25	75	18	34	11	12		
b144*	Memory functions	16	83	24	24	15	20		
b152*	Emotional functions	17	82	17	24	17	23		
b156*	Perceptual functions	37	63	19	20	12	12		
b160*	Thought functions	19	81	19	22	19	19		
b164*	High level cognitive functions	7	93	10	22	25	36		
b167*	Mental functions of language	48	52	21	13	7	12		
b210*	Seeing and related functions	71	29	15	9	4	2		
b215	Functions of structures adjoining the eye	77	23	10	8	5	1		
b230	Hearing functions	85	11	5	5	0	1	1	3
b235*	Vestibular functions	80	16	11	4	1	0	2	3
b280*	Pain	78	18	11	4	1	2		
b310	Voice functions	53	47	18	17	3	8		
b320	Articulation functions	50	50	19	15	6	10		
b330	Fluency and rhythm of speech functions	45	55	19	17	8	12		
b510	Ingestion functions	81	19	5	7	3	5		
b525*	Defecation functions	85	15	2	3	3	7		
b530	Weight maintenance functions	88	12	5	4	3	0		
b620*	Urination functions	80	20	5	2	2	12		
b640*	Sexual functions	56	13	3	1	3	6	10	21
b710	Mobility of joint functions	42	58	19	20	13	6		
b730*	Muscle functions	30	70	22	26	15	7		
b735	Muscle tone functions	41	59	23	17	16	3		
b750	Motor reflex functions	42	58	26	16	14	3		
b755	Involuntary movement reaction functions	50	50	17	16	15	4		
b760	Control of voluntary movement	47	53	18	12	17	6		
b765	Involuntary movement	55	45	15	12	13	6		
b8*	Skin functions	83	17	11	3	1	2		

ICF categories with a significant difference between in- and out-patients ($p < 0.001$) are printed in bold letters and are marked with "*".

Table 6
ICF categories in *Body Structures* from the Extended ICF checklist for TBI. Proportional distribution of patient answers (%)

ICF category	ICF titel	0	sum 1–4	1, mild	2, moderate	3, severe	4, complete	8, not specified	9, not applicable
s110*	Structure of the brain	4	96	15	39	31	12		
s2	The eye, ear and related structures	82	18	12	5	2	0		
s3	Structures involved in voice and speech	88	12	7	2	3	0		
s720	Structure of shoulder region	85	15	7	6	2	0		
s730	Structure of upper extremity	79	21	12	5	4	1		
s740	Structure of pelvic region	78	22	11	8	2	2		
s750	Structure of lower extremity	73	27	6	8	7	7		

ICF categories with a significant difference between in- and out-patients ($p < 0.001$) are printed in bold letters and are marked with "*".

For the component *activities and participation,* all the categories contained in the extended ICF checklist for TBI were identified as restricted in more than 10% of patients (100%). Seven out of nine chapters had at least one category that meant a problem by more than 80% of the patients: d1: *learning and applying knowledge*, d2 *general tasks and demands*, d4: *mobility*, d6: *domestic life*, d7: *interpersonal interactions and relationships*, d8: *major life areas* and d9: *community, social and civic life* (Table 7).

In the component environmental factors, 31 of 34 categories (91%) were named as facilitators by more than 10% of the patients examined. Only two categories were also named as barriers by more than 10% of the

Table 7

ICF-catgories in *Activities and Participation* from the Extended ICF checklist for TBI. Proportional distribution of patient answers (%)

ICF category	ICF title	0, no impairment	sum 1–4	1, mild	2, moderate	3, severe	4, complete	8, not specified	9, not applicable
d110	Watching	77	22	7	6	7	3		1
d115*	Listening	79	19	6	9	1	4		2
d140*	Learning to read	58	42	10	10	8	15		
d145*	Learning to write	39	61	19	18	8	16		
d150*	Learning to calculate	31	69	13	23	14	19		
d166*	Reading	48	52	16	14	13	11		
d175*	Solving problems	16	84	14	17	22	32		
d210*	Undertaking a single task	53	47	20	16	6	5		
d220*	Undertaking multiple tasks	16	84	30	15	19	20		
d230*	Carrying out daily routine	37	63	27	12	12	13		
d310*	Communicating with receiving spoken messages	66	34	16	14	1	4		
d315*	Communicating with receiving nonverbal messages	63	37	17	8	6	7		
d330*	Speaking	61	39	15	12	3	10		
d335	Producing nonverbal messages	63	37	16	8	7	7		
d345	Writing messages	48	52	16	12	9	17		
d350	Conversation	56	44	15	11	9	10		
d360	Using communication devices and techniques	64	36	8	11	4	14		
d410	Changing and maintaining body position	57	43	15	11	11	7		
d420	Transferring oneself	57	43	17	7	5	15		
d430	Lifting and carryng objects	49	51	11	12	14	16		
d440	Fine hand use	34	66	24	21	10	11		
d450	Walking	44	56	18	10	9	19		
d455	Moving around	46	54	14	12	10	19		
d465	Moving around using equipment	48	49	13	7	14	16		
d470	Using transportation	48	52	5	7	12	29		
d475	Driving	17	82	2	7	5	68		
d510	Washing oneself	50	50	14	10	13	15		
d520	Caring for body parts	46	54	15	14	9	17		
d530	Toileting	55	45	12	7	7	19		
d540	Dressing	47	53	19	4	13	17		
d550	Eating	60	40	16	11	4	10		
d560	Drinking	65	35	14	9	3	10		
d570	Looking after one's health	47	53	8	11	7	28		
d620	acquisition of goods and services	23	77	6	8	17	47		
d630	Preparing meals	19	80	17	13	15	35		
d640	Doing housework	18	81	11	17	13	41		1
d660	Assisting others	15	82	6	6	17	53		4
d710*	Basic interpersonal interactions	32	68	21	21	10	16		
d720*	Complex interpersonal interactions	13	87	12	25	15	36		
d730*	Relating with strangers	11	89	16	20	17	37		
d740*	Informal social relationsips	13	86	10	23	15	39		1
d750*	Informal social relationships	14	85	13	19	17	36		1
d760*	Family relationships	34	66	20	11	13	22		
d770*	Intimate relationships	17	68	7	12	13	37	8	7
d810*	Informal education	28	70	8	20	13	29	1	1
d820*	School education	19	78	9	14	18	37	1	1
d825*	Vocational training	16	83	15	12	17	39	1	1
d830	Higher education	8	90	3	11	8	69	1	1
d840*	Apprenticeship	12	86	14	9	18	46	1	1
d845*	acquiring, keeping and terminating a job	11	87	15	8	12	53	1	1
d850*	Remunerative employment	8	89	9	4	10	67	2	1
d860*	Basic economic transactions	17	83	11	15	13	45		
d865*	Complex economic transactions	8	92	10	5	12	66		
d870*	Economic self sufficiency	14	86	5	2	12	68		
d910*	Community life	22	78	12	15	19	32		
d920*	recreation and leisure	25	75	13	16	16	31		
d930*	Religion and spirituality	35	46	5	7	5	29	16	3
d940*	Human rights	25	58	2	7	5	45	16	1
d950*	Political life and citizenship	16	75	2	8	5	60	7	2

ICF categories with a significant difference between in- and out-patients ($p < 0.001$) are printed in bold letters and are marked with "*".

Table 8

ICF-catgories in *Environmental Factors* from the Extended ICF checklist for TBI. Proportional distribution of patient answers (%)

Environmental factors	Description	Barrier	Indifferent	Facilitator
e110*	Inmediate family	0.0	34.3	65.7
e115*	Products and technology for personal use in daily living	0.0	43.7	56.3
e120*	Products or substances for personal consumption	0.0	49.5	50.5
e125*	Products and technology for communication	1.0	81.6	17.5
e150*	design, construction and building products and technology of buildings for public use	4.9	57.3	37.9
e155*	design, construction and building products and technology of buildings for private use	2.9	56.3	40.8
e160*	Products and technology of land development	7.8	63.7	28.4
e165*	Assets	5.0	65.3	29.7
e310	Inmediate family	0.0	8.8	91.2
e320	Friends	5.8	32	62.1
e325	acquaintances, peers, colleagues, neighbours and community members	7.8	33.3	58.8
e330*	People in position of authority	1.0	22.5	76.5
e340*	Personal care providers and personal assistants	0.0	18.4	81.6
e355*	Health professionals	1.0	13.6	85.4
e360*	Health related professionals	0.0	25.2	74.8
e410	Individual attitudes of immediate family members	0.0	9.7	90.3
e420	Individual attitudes of friends	6.8	28.2	65.0
e440*	Individual attitudes of personal care providers and personal assistants	2.9	22.5	74.5
e450*	Individual attitudes of health professionals	1.0	17.5	81.8
e455*	Individual attitudes of health related professionals	2.0	25.5	72.5
e460*	Societal attitudes	23.3	44.7	32.0
e465*	Social norms, practices and ideologies	16.5	47.6	35.9
e525	Housing services, systems and policies	2.0	50.0	48.0
e535*	Communication services, systems and policies	1.9	66.0	32.0
e540*	Transportation services, systems and policies	7.8	55.3	36.9
e550	Legal services, systems and policies	1.9	33.0	65.0
e570	Social security, services, systems and policies	1.0	21.4	77.7
e575	General social support services, systems and policies	4.9	28.2	67.0
e580	Health services, systems and policies	0.0	18.4	81.6
e585	Education and training services, systems and policies	4.9	35.9	59.2
e590	Labour and employment services, systems and policies	9.8	42.2	48.0

ICF categories with a significant difference between in- and out-patients ($p < 0.001$) are printed in bold letters and are marked with "*".

patients: societal attitudes and social norms, practices and ideologies (e460 and e465) (Table 8).

3.1. Correlation of answers from EQ5D with extended ICF checklist

The linking exercise identified a much higher level of detail in the extended ICF checklist compared to the EQ5D. All correlations between the two questionnaires were significant (all $p < 0.01$) (Table 9).

3.2. Comparison between in-patients versus out-patients

The answers to 65 out of 150 categories from the extended ICF checklist (43%) showed significant differences between the in-patient and the out-patient groups (Tables 5–9). Differences in functioning and disability between the two patient groups lay predominantly in the ICF components of *Activities and Participation:* mobility, self-care, communication, inter-personal relationships and learning and applying knowledge, as well as in *Body Functions*: mental and sensory functions (Fig. 1).

4. Discussion

The aim of this cross-sectional study was to describe functioning and disability in patients after traumatic brain injury based on the ICF. The majority of categories (87%) from the extended ICF checklist for TBI were quantified as at least mildly impaired /restricted in more than 10% of the patients. This reflects the high diversity of problems that require a complex, multi-professional and comprehensive approach to TBI rehabilitation. The distribution of the problems within the ICF, showed a strong focus towards "body functions" and " activities and participations" and followed the same general pattern seen in previous studies [1,20,23]. The different aspects of functioning were compared between two patient groups: a) in-patients with mean time post-injury of of five months and b) out-patients with mean time post-injury greater than 6 years. This

Table 9
Correlation of EQ5D with ICF categories

EQ5D items	ICF categories	Level of significance (Pearson)	p-value (Pearson)
Mobility	d4, Mobility 0.32–0.62 (d410 changing body position, d 420 transferring oneself, d430 lifting and carrying objects d440 fine hand use d450 walking d455 moving around d465 moving around using equipm. d470 using tranportation d475 driving)	0.001–0.000**	
Self-care	d5 self-care (d510 washing oneself, d520 caring for body parts, d530 toileting, d540 dressing, d550 eating, d560 drinking d570 looking after one's health)	0.64–0.73	0.000**
Usual activities	d6, domestic life (d620 shopping, d630 preparing meals d640 doing housework d660 assisting others)	0.33–0.66	0.001–0.000**
Pain	b280, pain	0.32	0.001**
Anxiety	b152, emotional functions	0.26	0.008*

*P-value < 0.001 significant,
*P-value < 0.05 significant,
(ns): not significant with $p > 0.05$.

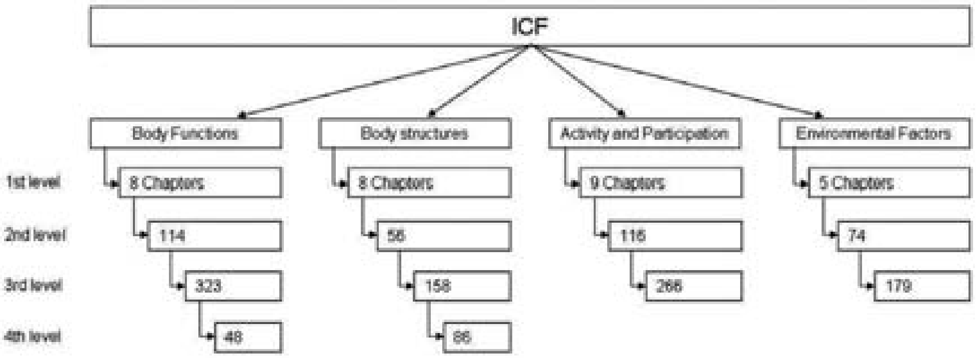

Fig. 1. Compounds of ICF. ICF categories of the extended ICF checklist for TBI that show significant differences between in-patients and out-patients ($p < 0.05$).

comparison may facilitate identification of which aspects of functioning might be more amenable to benefit from rehabilitation approaches than others. Some of these aspects (like learning and applying knowledge, mobility and self-care) are already included in most rehabilitation concepts, while others (like economic self-sufficiency or family relationships) might still wait for widespread implementation.

Consistent with the cognitive and behavioural involvement in TBI, more than 80% of the patients showed problems in *intellectual functions* (b117), *temperament and personality functions* (b126), *energy and drive functions* (b130), *memory functions* (b144), *emotional functions* (b152) and *high level cognitive functions* (b164). All these categories belong to the chapter of mental functions within *body functions* and underline the high relevance of mental functions for the rehabilitation process in patients after a traumatic brain injury. At the same time, the categories mentioned above are not only frequently impaired, but also show significant changes over time, moreso over the short than long term.

Body structures in TBI could be described with use of relatively few ICF categories. The scant presence of categories from body structures in TBI correlates with previous studies focused on TBI [1,23] and contrasts with other health conditions, for instance ankylosing spondylitis or even other neurological diseases such as stroke [18,38] in which the body structures show to have the same frequency of problems as the body functions.

Restrictions and limitations in the ICF component *activities and participation* seem to be most relevant to functioning and disability in patients after TBI. All areas of this domain were affected in the study population and emphasize the strong influence they have on patient‘s quality of life. More specifically, the areas related to *major life areas*, *interpersonal relationships* are named as a problem by more than 80% of the patients with a qualifier of 4 (total problem) and the majority of the patients of this study were not able to return to work after the injury. For people of working age, like the population of this study, employment is one of the most important aspects regarding participation. It has already been demonstrated that subjects that work show a better sense of wellbeing and quality of life [39]. Significant differences in functioning between patients in the shorter versus the longer term situation were identified in the ICF chapters: mobility, communication, self-care, major life areas (including work and employment and the economic situation), interpersonal relationships and learning and applying knowledge. Consequently, these aspects seem to offer good working points to orient rehabilitative approaches.

Chapter 9 (community, social and civic life) was relevant to more than 50% of the patients. However, in previous studies this domain has not been identified as relevant [1,23]. One explanation may be their use of retrospective data collected using clinical record documentation. The discrepancy between results of different studies may therefore reflect poor documentation in the clinical record rather than irrelevance of the domain. The description of problems based on this domain of the ICF may be of special interest to capture the limitations and restrictions in their normal life. It is already known that even though TBI patients show an increase of the general functioting over the time specially in the motor aspects, the cognitive areas normally remain impaired with time leading to problems regarding social integration [2,21].

Contextual environmental aspects, like the attitude of familiy members on patient functioning and rehabilitation following traumatic brain injury have already been elucidated in prior studies [17,31]. This study also showed that *family relationships* (e310) are of great importance indicating that it was a facilitator for more than 90% of the patients. At the same time, two thirds of the patients also reported problems with *family relationships* (d760). These results are consistent with previous studies of patients with neurological conditions and other mental health conditions such as stroke, bipolar disorders or depression [10,18]. There were also significant differences in the category d 760 (*family relationships*) showing the existence of more problems regarding the family in the outpatient group compared to the inpatient group. This is consistent with the nature recovery after TBI in which improvements in the proficiency of mobility or activities of daily life are not necessarily associated with improvements in relationships with family. Indeed, in many cases the relationships with the family enworsens with time [7,27].

Our study limitations include the fact that the ICF checklist was completed by observation and inferring the data through the interview of the patient. A family member was also usually present at the consultation and therefore, there coud have been a bias towards reporting functioning in a more positive than negative light. *Environmental factors* need to be studied more carefully. Research in environmental factors based on the ICF approach may be beneficial for conceptualizing interventions to be conducted in the post acute and social reintegration time.

5. Conclusion

This study identified the most common problems in a group of TBI patients based on the extended ICF checklist for TBI. We applied a prospective design to assess and compare rehabilitation outcome amongst shorter versus longer term patients The results emphasize the need to describe functioning and disability from a comprehensive perspective that not only includes *body functions and structures* but also *activities and participation* and contextual *environmental factors.* The rating of ICF categories with qualifiers can be used in a clinical multidisciplinary assessment as a way of standardization and understanding the patient's functioning. Moreover, the ICF will also provide a tool for distributing responsabilities within the rehabilitation team, assign intervention targets and evaluate the rehabilitation proccess.The future application of the ICF in patients with TBI might be substantially supported if there was a condition-specific tool like the ICF Core sets for TBI.Future research should focus on operationalization of the ICF in clinical practice through the development of electronic documentation systems and the assigment of standardized instruments to the ICF.

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RESEARCH ARTICLE

ICF profiling of patients with traumatic brain injury: an international professional survey

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Abstract

Purpose: A worldwide internet survey was conducted (1) to identify problems of individuals with traumatic brain injury (TBI) addressed by health professionals and (2) to summarize these problems using the International Classification of Functioning, Disability and Health (ICF). *Method*: A pool of professionals involved in the TBI rehabilitation process that included physicians, nurses, physical therapists, occupational therapists, social workers and psychologists were surveyed to identify problems in functioning and contextual factors of individuals with TBI using open-ended questions. All answers were translated ("linked") to the ICF based on established rules. The frequencies of the linked ICF categories were reported stratified based on context. *Results*: One-hundred thirty seven professionals from the six World Health Organization regions identified 5656 concepts. 92.66% could be linked to the ICF; 33.03% were related to the domain of body functions, 27.28% to activities and participation, 10.98% to structures and 21.38% to environmental factors. *Conclusions*: The complexity of TBI was described through the identification of a wide variety of ICF categories. ICF language proved to be a neutral framework allowing the comparison of answers between different professionals in different world regions.

Keywords

Core sets, international classification of functioning, traumatic brain injury, World Health Organization

History

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➤ Implications for Rehabilitation

- People that suffered a traumatic brain injury (TBI) may have a variety of sequelae that impair functioning. The International Classification of Functioning, Disability and Health (ICF) can help in providing information regarding the identification of patients problems and needs as well as planning, implementing and coordinating the rehabilitation process.
- The ICF provides a frame of reference process illustrated as the rehabilitation cycle that can help during the rehabilitation process in goal setting bringing together the clinicians' and patient's perspectives in a patient oriented biopsychosocial approach.
- In the field of TBI rehabilitation, activity limitations and participation restrictions are broadly affected as reported by the professionals interviewed and highly influenced by cognitive and moreover behavioral problems.

Introduction

Traumatic brain injury (TBI) is one of the leading causes of disability in developed countries with an estimated prevalence of 5.3 million people in the USA and 7.3 million people in Europe [1]. TBI can produce a wide spectrum of both symptoms and signs that may change across time. TBI recovery may follow a variable course and outcomes are often challenging to prognosticate [2,3]. Patients with this neurological condition need both medical and rehabilitation management which ideally should be provided by an interdisciplinary or transdisciplinary medical and rehabilitation team.

Typically, physicians, nurses, neuropsychologists and other health professionals need to assess the patients' global functioning in order to best provide individualized interventions that will constitute a rationale rehabilitation program. Optimal rehabilitation management relies on an understanding of the patients' functioning that includes defining impairments in areas such as cognitive (i.e. mental), sensory and/or musculoskeletal functions, seizures, behavioral problems and/or endocrine disorders. Despite the clearly evident need for a multidisciplinary approach to the treatment of such patients, there is still no instrument that comprehensively and uniformly describes the experience of persons with this health condition. Therefore, it is important for the rehabilitation team to share a common language to describe

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functioning in order to develop programs to decrease TBI related disability [1,4–7].

The International Classification of Functioning, Disability and Health (ICF) offers a universal framework to describe functional status based on a biopsychosocial model of disability [8]. The ICF is important in that it conceptualizes functioning and disability and complements other classifications from the World Health Organization (WHO) such as the International Classification of Diseases with an etiological orientation. The ICF, within the components *of Body Structures*, *Body Functions*, *Activities and Participation*, as well as *Environmental Factors,* can serve as a comprehensive starting point to describe the functional status of patients with TBI. Given the extension of the classification, practical tools such as the Core Sets are needed. The ICF Core Sets are being developed for specific health conditions and are composed of selected categories from the entire classification that can best describe patient profiles.

Following the instructions of the ICF Research Branch in Munich, the ICF Core Sets were developed through a decision making process at a consensus conference with data being acquired through four different studies. These studies aimed to gather information from patient, researcher and clinician perspectives, as well as from an empirical patient study. The Consensus Conference for TBI was held in Barcelona in March 2010 and gathered information from the following studies:

1. Qualitative study with focus groups and personal interviews to capture the patient perspective and identify those aspects of functioning, disability and environmental factors that were important to persons with TBI [9,10].
2. Systematic literature review to capture researcher focus based on publications in dealing with TBI [11].
3. Empirical study aimed at describing the functional profile of patients with TBI based on the ICF [5,12].
4. Expert survey to explore professional views and current study.

The aim of our overall study was to explore the aspects of health and functioning that were most relevant to patients with TBI from the point of view of health professionals with experience in treating persons with this neurological condition. Another study aim was to identify the areas of functioning considered as problematic and/or the environmental factors that affected the lives of persons after TBI utilizing the ICF [4,5].

Methods

Study design

An international professional internet survey was conducted. Physicians, nurses, physical therapists, occupational therapists, social workers and neuropsychologists participated in order to develop adequate cross-disciplinary perspectives from a cross-section of the rehabilitation team. Electronic mail was chosen in order to facilitate timely and cost-effective data collection. Health professionals had to meet the following criteria to be included as ''experts'' in the survey: (1) Participants were qualified as a nurse, physical therapist, occupational therapist, social worker, neuropsychologist or physician (regardless of specialization); (2) At least 5 years clinical experience treating individuals with TBI and (3) Fluent in English (even if not their first language).

Considering the universality of the ICF and taking into account the different regional perspectives, the expert survey was done utilizing professional sampling in the six regions of the WHO (http://www.who.int/about/regions/en/index.html).

Experts from the Eastern Mediterranean, South East Asia, Western Pacific, the Americas, Africa and Europe were included in this study based on the WHO regions.

The selection of experts was performed in two successive steps. In the first step of the recruitment, international organizations in the field of TBI were identified and the representatives from the organizations were contacted and asked to provide the names of experts. Other experts were contacted directly through referral by the study steering committee based on recognized expertise in the field or based on knowledge of that expert's peer reviewed scientific publications. The potential candidates received an e-mail including detailed information about the survey and study. All experts who agreed to participate were included in the study.

Measures

The internet survey consisted of two questionnaires. The first part addressed participant information and professional background, while the second part included a questionnaire to gather data regarding perceived impairments in persons after TBI. The questions in the expert survey included the following:

1. If you think about the body and mind of individuals with TBI what does not work the way it is supposed to?
2. If you think about the body of individuals with TBI, in which parts are their problems?
3. If you think about the daily life of individuals with TBI, what are their problems?
4. If you think about the environment and the living conditions of individuals with TBI, what is supportive and/or what is hindering for them?
5. If you think about individuals with TBI, what is important about them and the way they handle their condition?

Data collection

The expert survey was conducted between January 2009 and January 2010. The experts that agreed to participate were sent a user name and password to get access to the survey website. A hard copy of the survey was provided if there were any technical problems while entering the data. All answers were anonymous and maintained as such.

Data analysis

The functional concepts identified from the answers of the experts were linked to the ICF classification according to the linking rules [13,14]. Initially, the answers were reviewed to get an overall sense of the data and the dominant concepts were identified. If an answer contained more than one concept, then each concept was named and analyzed separately. Each concept was linked to the ICF category that best defined it. If a response was too general to be specified by an ICF category, then it was coded as ''not defined''. Responses related to personal factors such as ''perception of the patient's well-being'' were coded as a ''personal factor''. If an answer reported an aspect of functioning that was not covered by ICF, then it would be demarcated as ''not covered'' (physical functioning). Responses related to a health condition were not classifiable using the ICF and were therefore coded as a ''health condition''.

The concepts reported by each of the professional categories were analyzed separately.

Quality assurance procedures

The main researchers involved in the linking procedure were trained in a 2 week workshop performed by team members of the ICF Research Branch Munich. The identification of the concepts and linking was done by SL and VR. Disagreement was solved by consensus after discussion with RL and MB.

Results

Participants

A total of 486 experts were contacted in 54 different countries. One hundred thirty seven agreed to participate in the study and completed the study survey; however, 30 expert surveys were excluded because their work was not completed by the study deadline; one hundred and seven (78.1%) expert responses were therefore included in the study. The demographic and professional characteristics of the included experts are provided in Table 1.

Table 1. The demographic and professional characteristics of the experts that participated in the electronic survey.

Demographic results $n = 107$	
Gender (female)	50.8% (n53)
Age	41.7 years SD 14
Professional experience	15.2 years SD 7.4
Profession	
Medical doctor	32.7% (n35)
Neuropsychologist	20.5% (n22)
Nurses	5.6% (n6)
Occupational therapy	11.2% (n12)
Physiotherapist	16.8% (n18)
Social Worker	3.7% (n4)
Speech therapist	9.3% (n10)
*Professional activity**	
Clinical practice	81.3% (n87)
Research	13.0% (n14)
Management	5.6% (n6)
Education	5.6% (n6)

*Some professionals may be in different professional activities.

Linking of problems

A total of 5656 concepts were retrieved after analyzing the answers provided by the experts. From these concepts, 92.66% ($n = 5241$) of concepts could be linked to ICF factors, whereas, 7.34% ($n = 415$) did not meet criteria to be linked to any ICF factors. From this total, 1.26% ($n = 72$) were linked to personal factors, 6.06% ($n = 343$) were non-codified, and 0.02% ($n = 1$) were related to health factors (Table 2).

The majority of the answers were linked to the domain of *body functions* ($n = 1868$, 33.03%) followed by *activities and participation* ($n = 1543$, 27.28%), then *environmental factor*s ($n = 1209$, 21.38%) and *body structures* ($n = 621$, 10.98%).

The majority of the concepts ($n = 3979$, 70.35%) were linked to second level categories; whereas, 14.14% ($n = 800$) were linked to categories from the third level.

Figures 1–4 describe the differences in the areas reported by the different professionals. In Figure 1, the impairments of body functions by chapter as reported by the experts show that mental functions, followed by musculoskeletal functions and sensory functions were the most frequently named areas of impairment. Consistent with previous findings, Figure 2 describes the impairments of body structures which are proportional to the impairments in *body functions* except for the fact that impairments in speech and language functions were noted at a higher rate by experts in speech therapy relative to other expert specialty groups. Structures related to chapters 4, 5 and 6 regarding cardiovascular, hematological, immunological, respiratory, digestive, endocrinology and genitourinary functions were named mainly by nurses and physicians. Figure 3 shows the domain of activity and participation as problematic in all the different chapters with some differences according to the

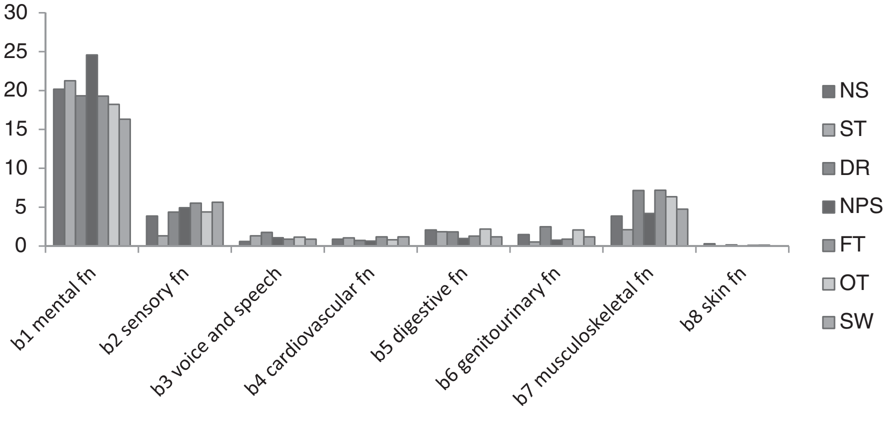


Figure 1. Distributions of concepts reported by different group professionals regarding the different chapters of body functions. The columns represent the percentage of concepts reported by each group. NS (nurses), ST (speech therapists), DR (doctors), NPS (neuropsychologists), FT (physiotherapist), OT (occupational therapist) and SW (social worker).

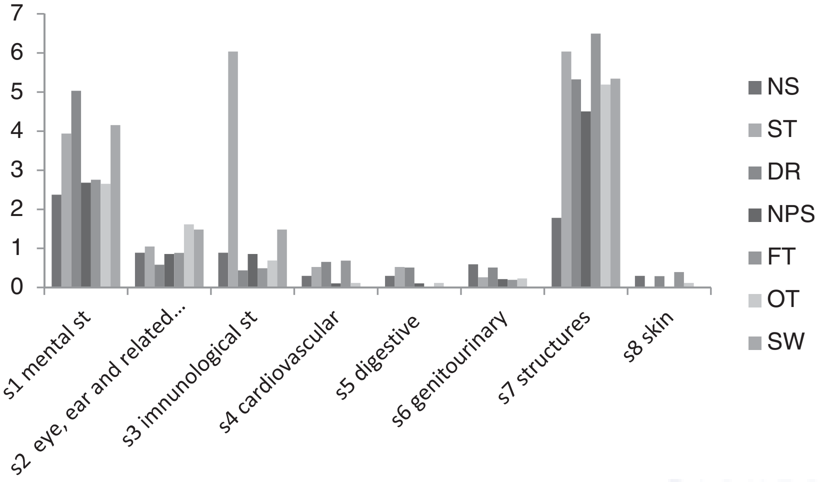


Figure 2. Distributions of concepts reported by different group professionals regarding the different chapters of body structures. The columns represent the percentage of concepts reported by each group.

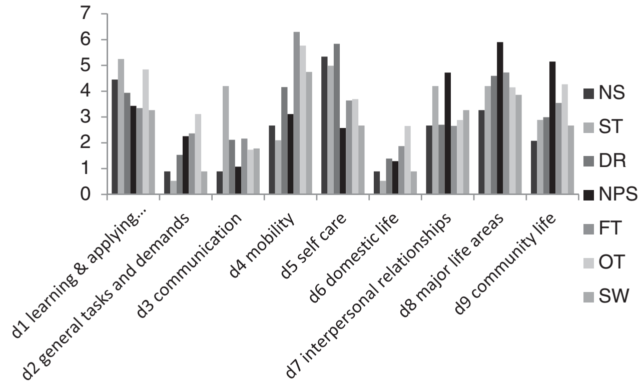


Figure 3. Distributions of concepts reported by different group professionals regarding the different chapters of activities and participation. The columns represent the percentage of concepts reported by each group.

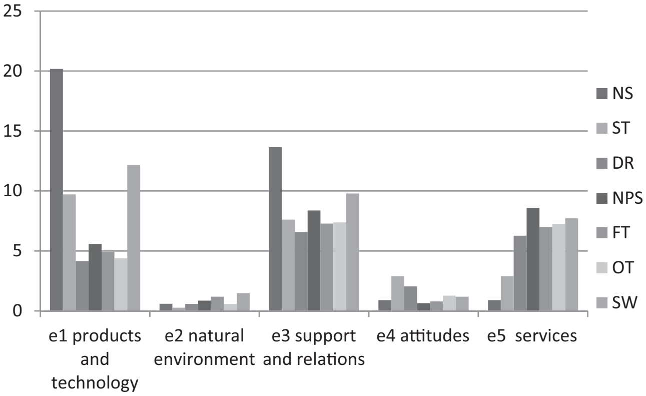


Figure 4. Distributions of concepts reported by different group professionals regarding the different chapters of environmental factors. The columns represent the percentage of concepts reported by each group.

professional group. Figure 4 illustrates that professionals highlight the areas of ‘‘products and technology’’, ‘‘support and relationships’’ and ‘‘services, systems and policies’’ as the most important environmental factors implicated in the functioning of persons with TBI. Figure 5 describes the categories that were named by more than 20% of the participants distributed by the domains of *body functions*, *structures*, *activities and participation* and *environmental factors*. The 20% demarcation was used as a cut off in previous studies [12].

Discussion

This is the first survey that explores the functional problems of individuals with TBI from an international and multidisciplinary perspective using the ICF as a reference. The main reason the ICF was used in this study was due to the fact that it provides a neutral framework and has already been used in many studies to describe the experience of health utilizing a common language for health and disability data [11,15].

The experts that participated in this survey had different professional backgrounds and came from 49 different countries, which allowed inclusion of multicultural points of view. The percentage of professionals that agreed to participate in our study and also completed the e-survey was very high (79.2%) compared to other studies [16,17].

As expected, the experts addressed a wide spectrum of aspects in functioning and health, reflecting the complex spectrum of TBI sequelae. Cognitive, emotional, behavioral, physical, as well as psychosocial factors all interact to impact functional status after TBI [18–20]. Since TBI can potentially be associated with lifelong impairment and functional disability, its consequences may generate different needs including differing levels of professional support across the patient’s lifespan. The use of the ICF can help in defining any given patient’s global situation, as well as their needs.

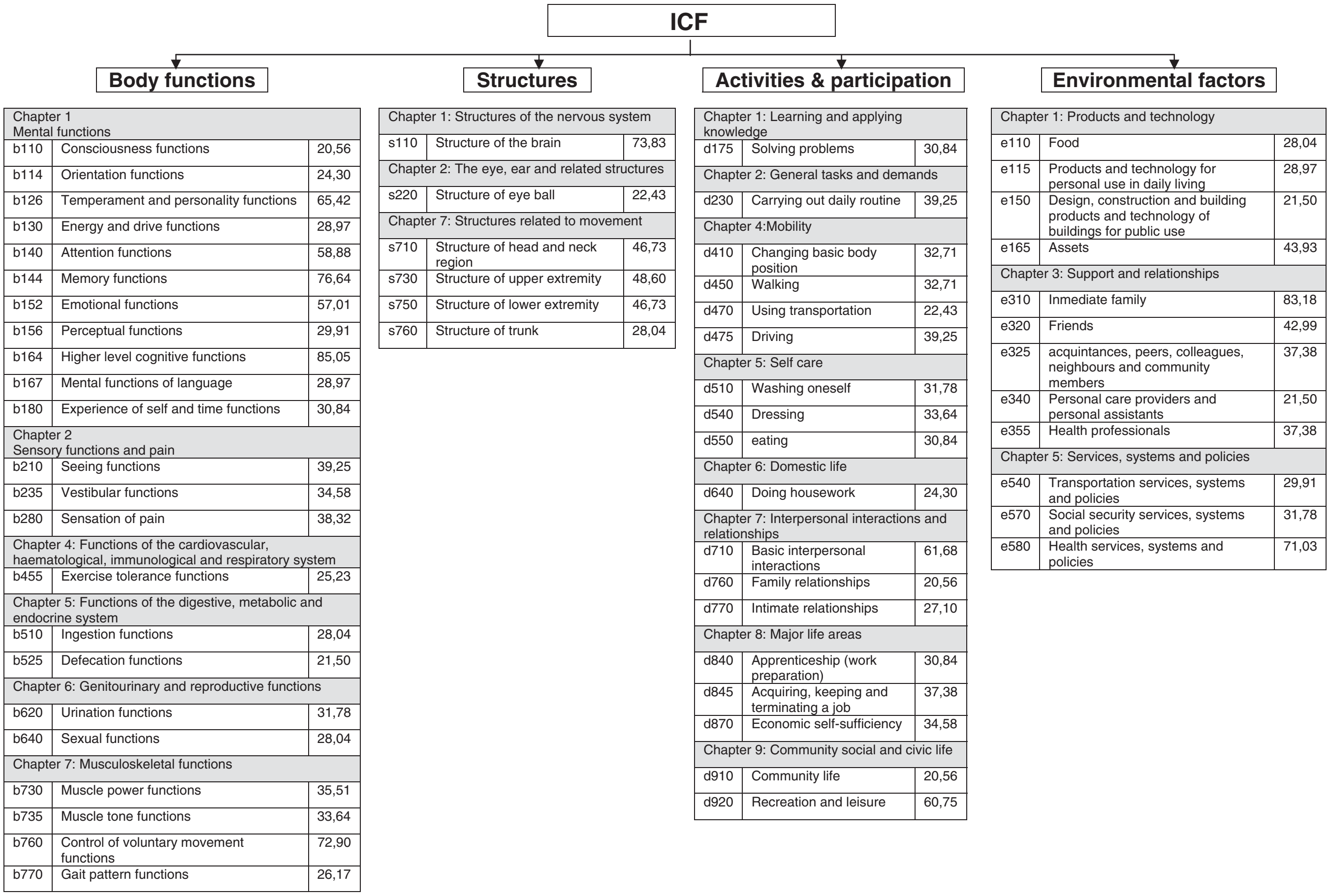
The majority of the experts’ answers were linked to categories of the domain of *body functions* (33.03%). All the chapters from this domain were at least named once and six out of the eight chapters had categories that were named by more than 20% of the participants with particular focus on *mental functions* and *musculoskeletal functions.* As shown in Figure 1, there is still an apparent tendency of focusing on problems associated with body functions suggesting that the ‘‘medical model’’ of disability is still quite prevalent among those professionals dealing with TBI. If this profile is compared with the ICF functioning profile described in the article by Laxe et al. [5], one can see a gap in the assessment of areas related to the domain of activities and participation that have shown to be relevant in the assessment of functioning of patients after TBI.

Consistent with previous studies regarding TBI, cognitive functions such as processing speed, memory, attention, awareness, lack of self-awareness were the items that constantly appeared in the answer of the first question ‘‘What do you think about the body and mind of individuals with TBI?’’ Cognitive impairments are common sequelae after TBI and represent one of the most important reasons why such patients have a reduction in participation [21]; therefore, it was also not surprising that 85.05% of the experts mentioned the category b164 *Higher level cognitive functions.* Moreover, these functions, when impaired, are associated with a poorer rehabilitation outcome [6,22,23]. Commensurate with the aforementioned, other frequently named categories were *b 126 temperament and personality functions* and *b144 memory functions*. Figures 2–5 indicate differences in the expert responses further supporting the need for a multidisciplinary approach to care in order to develop a more comprehensive view of patient functioning and needs. When analyzing the domain of activities and participation, mobility ‘‘d4’’ was mentioned more by physiotherapists and occupational therapists, while communication ‘‘d3’’ was mentioned more by speech therapists. Neuropsychologists identified ‘‘d7’’, ‘‘d8’’ and ‘‘d9’’ which are related to patient societal participation and complex activities of the daily living (e.g. managing one’s finances, interpersonal or working relations) as most problematic.

Skin problems have not been commonly referred to in brain injury studies and in our survey they were named exclusively by nurses, except for one physician, showing that in their clinical practice, the risk of pressure ulcers were normally items that the nurses took care of and identified with. Contrary to the aforementioned, some categories involving skin structure problems were named more frequently by physicians and physiotherapists as related to restrictions of the skin and/or soft tissue that limited passive range of motion.

Other, no less important problems, such as dizziness, diplopia, pain or fatigue were captured in the categories *b120 Seeing functions, b235 Vestibular functions, b280 Sensation of Pain* and *b455 Exercise tolerance functions.* With regards to neuromusculoskeletal functions, [24], the most frequent categories reported were b730 *Muscle power functions,* b735 *Muscle tone functions,* b760 *Control of voluntary movement functions* and b770 *Gait pattern functions* that address problems such as spasticity, loss of coordination of the voluntary movements, as well as gait abnormalities.

When the professionals were asked about the impairments of structures that affected the rehabilitation of patients with TBI,



Body functions

Chapter 1 Mental functions		
b110	Consciousness functions	20,56
b114	Orientation functions	24,30
b126	Temperament and personality functions	65,42
b130	Energy and drive functions	28,97
b140	Attention functions	58,88
b144	Memory functions	76,64
b152	Emotional functions	57,01
b156	Perceptual functions	29,91
b164	Higher level cognitive functions	85,05
b167	Mental functions of language	28,97
b180	Experience of self and time functions	30,84
Chapter 2 Sensory functions and pain		
b210	Seeing functions	39,25
b235	Vestibular functions	34,58
b280	Sensation of pain	38,32
Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory system		
b455	Exercise tolerance functions	25,23
Chapter 5: Functions of the digestive, metabolic and endocrine system		
b510	Ingestion functions	28,04
b525	Defecation functions	21,50
Chapter 6: Genitourinary and reproductive functions		
b620	Urination functions	31,78
b640	Sexual functions	28,04
Chapter 7: Musculoskeletal functions		
b730	Muscle power functions	35,51
b735	Muscle tone functions	33,64
b760	Control of voluntary movement functions	72,90
b770	Gait pattern functions	26,17

Structures

Chapter 1: Structures of the nervous system		
s110	Structure of the brain	73,83
Chapter 2: The eye, ear and related structures		
s220	Structure of eye ball	22,43
Chapter 7: Structures related to movement		
s710	Structure of head and neck region	46,73
s730	Structure of upper extremity	48,60
s750	Structure of lower extremity	46,73
s760	Structure of trunk	28,04

Activities & participation

Chapter 1: Learning and applying knowledge		
d175	Solving problems	30,84
Chapter 2: General tasks and demands		
d230	Carrying out daily routine	39,25
Chapter 4:Mobility		
d410	Changing basic body position	32,71
d450	Walking	32,71
d470	Using transportation	22,43
d475	Driving	39,25
Chapter 5: Self care		
d510	Washing oneself	31,78
d540	Dressing	33,64
d550	eating	30,84
Chapter 6: Domestic life		
d640	Doing housework	24,30
Chapter 7: Interpersonal interactions and relationships		
d710	Basic interpersonal interactions	61,68
d760	Family relationships	20,56
d770	Intimate relationships	27,10
Chapter 8: Major life areas		
d840	Apprenticeship (work preparation)	30,84
d845	Acquiring, keeping and terminating a job	37,38
d870	Economic self-sufficiency	34,58
Chapter 9: Community social and civic life		
d910	Community life	20,56
d920	Recreation and leisure	60,75

Environmental factors

Chapter 1: Products and technology		
e110	Food	28,04
e115	Products and technology for personal use in daily living	28,97
e150	Design, construction and building products and technology of buildings for public use	21,50
e165	Assets	43,93
Chapter 3: Support and relationships		
e310	Inmediate family	83,18
e320	Friends	42,99
e325	acquintances, peers, colleagues, neighbours and community members	37,38
e340	Personal care providers and personal assistants	21,50
e355	Health professionals	37,38
Chapter 5: Services, systems and policies		
e540	Transportation services, systems and policies	29,91
e570	Social security services, systems and policies	31,78
e580	Health services, systems and policies	71,03

Figure 5. Description of categories in the second level that were named by the participants with a frequency more than 20%.

Table 2. Distribution of the concepts linked to the ICF.

Description of the concepts identified							
		HC	PF	NC		Total	
Not codified $n = 415$		1	72	343		415	7.34%
Codified $n = 5241$		Chapter	2nd level	3rd level	4th level	5241	92.66%
	Body functions	20	1426	417	5	1868	33.03%
	Body structures	29	442	144	6	621	10.98%
	Activity & Participation	283	1099	161	0	1543	27.28%
	Environmental factors	118	1012	78	1	1209	21.38%
Total $n = 5656$	5656	450	3979	800	12	5241	100%

HC: health condition, PF: personal factor, NC: non codified.

the *Structure of the brain (s110)* accounted for the majority of the answers but almost half of the participants of the survey agreed that problems in the structure of the head and neck (*s710*), as well as in the upper and lower extremity (*s730* and *s750*, respectively) were the most common impairments. Restrictions in range of movement from neck muscles, as well as limitation in movement of the upper and lower extremities were reported as problems by more of the 40% of the survey participants.

Limitation in eye movements (s220) due to problems with cranial nerve function, as well as shearing of the neural pathways involved in vision or injuries to the optic nerves or retina producing a visual impairment were noted by 22.43% of the survey participants [25].

Besides description of impairments of the body functions, the experts polled emphasized aspects from the patient's daily activities that were already reflected in previous studies [26,27]. The impairment of neurological and cognitive functions has already been shown to lead to activity limitations and participation restrictions. The experts regularly reported that impairments involving impulsivity, irritability, and lack of frustration tolerance were present in the daily life of patients after TBI. These answers correlate with the evidence of previous studies [28] in which disability levels among persons with TBI was shown to be highly related to cognitive impairment and that these types of impairment were a substantial source of familial stress [29]. The lack of participation in normal routine activities is therefore an important aspect of functioning or lack thereof after TBI.

In addition to the above-mentioned areas regarding *body functions*, all the chapters from the domain of *activities and participation* were cited by the participants in response to the third question ''What are the problems in the daily life of individuals with TBI?'' All chapters except chapter 3

(Communication) were named in more than 20% of the cases. This number may seem surprising but it may be explained by the fact that the majority of the professionals that reported issues in this area were speech therapists. Interpersonal interactions, problems in interacting with other people, social skills and social interactions, all of which were included in category *d710 Basic inter-personal interactions,* accounted for 61.68% of the responses. Recreational activity restrictions were noted by 60.75% of experts polled.

Solving problems, carrying out daily routines, problems in mobility and self-care, as well as limitations in domestic life were also frequently reported as seen in Figure 5. Previous studies have shown that mental health, employment, leisure and social relationships were the strongest long term predictors of quality of life after TBI. Additionally, lower levels of life satisfaction have been reported in individuals following TBI who could not live independently, needed caregivers or were unable to return to their pre-injury jobs [30].

When examining the impact of environmental factors, the survey participants noted the importance of the immediate family (e310), as well as health and social services (e5). The role of the family and caregivers during the rehabilitation process was noted by the survey experts as an important factor influencing the patient's functioning. The attitude of family members, their support, as well as their own coping styles have been the object of previous studies that have shown an association with the overall outcome after TBI [31]. Environmental factors can facilitate or serve as a barrier for persons with TBI. Although such factors have been examined in prior literature, no analysis of same was done in our study [1,5,32].

The experts also remarked on how behavioral and emotional factors including loss of motivation, anxiety or depression (b126 temperament and personality functions and b152 emotional functions) influenced the interaction between the person and the environment. The aforementioned finding strengthen the rationale for using a comprehensive model such as the ICF to facilitate new insights into the description of overall functioning of patients after TBI.

Further important aspects of the patients with TBI were found to be related to personal factors. Statements like ''identify what is a problem and what is not'', ''admit limitations'', ''resilience'', ''willingness to engage a rehabilitation program'', ''capacity of readjustment'' or ''self-esteem'' were captured by the health professionals as personal factors that played a role in the adaptation process after brain injury. Previous studies have reported emotional feelings such as avoidance, distraction or preoccupation to be associated with higher levels of anxiety and depression and, therefore, worse functional outcome [33].

There are a number of limitations to this study, which should be acknowledged as related to our conclusions and as relevant to similar studies. Firstly, the sample of experts was not homogenous with less representation of nurses, occupational therapists and speech therapists relative to other professional disciplines involved with TBI rehabilitation. Secondly, the professional sample may be overrepresented by experts from developed countries [16], which may more heavily weight opinions associated with a different standard of health and/or societal care than seen in less developed regions of the world that may not have sophisticated systems of care for persons with TBI.

Conclusions

This study demonstrated the complexity of the symptoms and deficits that persons with TBI experience from the point of view of the professional. The ICF was able to structure the information gathered from the interview confirming that the ICF is a useful tool in describing functioning in a neutral and consensus derived framework. The determination of patient problems using a common language is of special interest in both multidisciplinary management, as well as policy making regarding persons with TBI but is also useful in comparing functioning profiles across other health conditions.

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Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this article.

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Development of the International Classification of Functioning, Disability and Health core sets for traumatic brain injury: An International consensus process

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Abstract

Background: In a patient-oriented healthcare system, the integration of the functional status of the patient from the perspective of different professionals is understandable by the use of the International Classification of Functioning, Disability and Health.
Objective: A formal decision-making and consensus process is presented to develop the first version of the International Classification on Functioning, Disability and Health (ICF) Core Sets for Traumatic Brain Injury.
Method: A panel with the results from preparatory studies that included a literature review, a qualitative study, empirical data collection and an expert survey, was presented. A consensus conference was held in Barcelona, March 2010 and 23 professionals attended representing nine countries.
Results: The preparatory studies identified 183 eligible categories. After the voting process, 139 constituted the Comprehensive Core Sets for TBI and 23 the Brief Core Sets for TBI.
Conclusions: The consensus conference led to the integration of evidence and expert opinion based on the ICF. The adoption of the ICF Core Sets for TBI provides a basic international standard for the multidisciplinary assessment of a TBI patient's functioning.

Keywords: *Traumatic brain injury, ICF, ICF core sets, functioning and disability, consensus conference*

Introduction

Traumatic brain injury (TBI) is a major public health problem, being the most common cause of disability and death among young people [1].

TBI is characterized neuropathologically by both focal and diffuse damage produced by an external force and may cause a spectrum of impairments ranging from disorders of consciousness, to sensorimotor, cognitive, linguistic and/or behavioural problems that may be further associated with an array of disabilities [2].

Neurocognitive and neuropsychiatric impairments tend to be associated with greater disability and societal challenges in comparison with other impairments, particularly with respect to their impact on

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psychosocial and vocational reintegration [3–6]. TBI may result in limitations of an individual's daily activities and restrictions in participation in life situations, leading to an overall decrease in perceived quality-of-life [7]. Over time, functional improvements may occur. However, residual impairments and disabilities may prevent optimal community reintegration [8].

A major issue for professionals working with persons with TBI concerns the diverse patterns of impairment and disability after TBI and the large variation in the currently available measures. There is little standardization in the use of these instruments and, therefore, performing comparisons across studies from different centres and countries is challenging, if not impossible [9, 10].

To avoid this and with the approval in 2001 of the International Classification of Functioning, Disability and Health (ICF) by the WHO, there is a universally accepted framework to describe functioning, disability and health.

The ICF was developed to address the impact of health conditions from a biopsychosocial perspective and shifted the paradigm of health, disability and disease to a more comprehensive concept involving biological, psychological, social and environmental aspects [11].

As a classification, its taxonomy is divided into two parts. Part 1 covers Functioning and Disability and Part 2 covers the Contextual Factors. The ICF contains an exhaustive list of globally acceptable descriptions of what can be relevant to describe functioning, disability and health. The ICF is hierarchically organized and distributed within different domains. In part 1 there are 493 categories describing *body functions* (*b*), 310 *body structures* (*s*) and 393 describing *activities and participation* (*d*) domains. Part 2 is divided into *environmental factors* (*e*), that comprise 258 categories, and *personal factors*, which have not been identified so far. The taxonomy of the ICF includes a letter which represents the domain: *b*, *s*, *d* or *e*, followed by a number that indicates the level of hierarchy and description, as seen in the following example:

b1, *mental functions*: first chapter/level.
    b114, *orientation functions*: second chapter/level. General mental functions of knowing and ascertaining one's relation to self, to others, to time and to one's surroundings.
        b1142, *orientation to person*: third chapter/level. Mental functions that produce awareness of one's own identity and of individuals in the immediate environment.
            b11420, *orientation to self*: fourth chapter/level. Mental functions that produce awareness of one's own identity.
            b11421, *Orientation to others*: fourth chapter/level. Mental functions that produce awareness of the identity of other individuals in one's immediate environment.

The ICF contains a total of 1454 ICF categories, consequently becoming too broad to be used in a practical way. Therefore, tools based on the ICF are recommended for the operationalization of the ICF which includes the development of the ICF Core Sets for specific conditions [12].

The project to develop a core set for TBI based on the International Classification of Functioning, Disability and Health (ICF) was driven by the desire to define salient outcome data points; that is, the essential domains of functioning and disability that should be considered when describing the impact of TBI on the individual [12]. Determining what needs to be measured should proceed independently from the measurement process *per se*. For example, the question of whether the 'level of consciousness' is an important domain to assess when examining the impact of TBI on an individual can be answered independently from the question of the best method to measure the degree or nature of the impairment in consciousness (e.g. a neurobehavioural questionnaire, fMRI or PET scan).

The ICF can help in describing the complexity of functioning of persons with TBI since it is able to capture a person's impairments in body functions and structures, activity limitations and restrictions in participation, as well as environmental factors. Accordingly, the ICF was used as a starting point for the selection of domains to be measured because it is a classification structure designed by the World Health Organization (WHO) that provides an international and common vocabulary for comprehensively describing the degree of functioning, from specific body functions and structures to activities and areas of participation that may be affected by a health condition. The ICF also considers the interaction of the aforementioned components with environmental factors (including physical, attitudinal and social environments), as well as personal factors such as age, gender, life experience and coping style. In short, the ICF provides clinicians and researchers, disability managers and policymakers and other stakeholders with a comprehensive framework to identify and illustrate relevant domains of human experience that are affected by health conditions such as TBI, in the context of environmental and personal factors [13–15].

The ICF Core Set project for TBI was a collaborative effort between the Guttmann Institute Hospital for Neurorehabilitation-Universitat Autónoma de Barcelona, the ICF-WHO Research Branch, the International Brain Injury Association

(IBIA) and the International Society of Physical and Rehabilitation Medicine (ISPRM) [9].

Comprehensive and brief ICF core sets for traumatic brain injury

The Comprehensive ICF Core Set for TBI is a list of ICF categories that includes as few categories as possible to be practical, but as many as necessary to describe the aspects of functioning relevant to persons with TBI in a comprehensive, multidisciplinary assessment. While the Comprehensive ICF Core Set for TBI was designed as a guide for multidisciplinary assessments of persons with TBI, the Brief ICF Core Set for TBI was designed to be used when a brief description and assessment of functioning of a person with TBI is sufficient (e.g. clinical documentation or in epidemiological studies).

The Brief ICF Core Set for TBI is derived from the Comprehensive ICF Core Set and is a list of ICF categories that serve as a minimal international standard for the reporting of functioning in persons with TBI along the continuum of care (ranging from the acute hospital through to community reintegration) and across sectors (health, labour and social affairs).

The objective of this paper is to report the results of the evidence-based consensus process to develop the first version of the Comprehensive and Brief ICF Core Sets for TBI.

Methods

The ICF Core Sets for TBI were developed following a multi-stage, formal decision-making and consensus process [9, 16–19] that integrated evidence gathered from four preliminary studies.

Preliminary studies

The preliminary studies were performed in order to examine which ICF categories were considered relevant to people with TBI from four different perspectives:

(1) The patient perspective, which was captured through a qualitative study, included 14 focus groups and four personal interviews with patients who experienced sequelae from TBI. The aim of the qualitative study was to identify those aspects of functioning, disability and environmental factors that were important to persons with TBI. The number of focus groups and interviews was determined by the saturation by which the items reported by the participants did not raise new concepts. Focus groups were preferred to single interviews. The interaction between the participants usually provided more information than individual interviews as the participant comments often generated further commentary from others in the group. However, in light of attention and behavioural impairments of patients with TBI, up to four personal interviews were conducted [20, 21].

(2) The health professional perspective was explored with an internet-based expert survey that included the response from 107 health professionals from 55 different countries across the six WHO regions. Regarding the professional background of the participants, 35 (32.7%) were medical doctors, 22 (20.5%) were neuropsychologists, six (5.6%) were nurses, 12 (11.2%) were occupational therapists, 18 (16.8%) were physiotherapists, four (3.7%) were social workers and 10 (12%) were speech therapists.

(3) The perspective of researchers was examined through a systematic literature review. According to a systematic selection procedure, 105 publications describing studies involving persons with TBI were included in the analysis to identify the concepts contained in the parameters and outcomes reported in the studies. These concepts were then linked to the ICF [22].

(4) The clinical perspective was explored through empirical data collection by applying the ICF checklist to 500 patients with TBI (48 patients were recruited in Norway, 88 in Australia, 103 in Spain and 261 in Italy) [23, 24].

Based on these preliminary studies, a pre-selection of ICF categories was established. The ICF categories chosen served as the starting point for the decision-making and consensus process during an international conference that took place in Barcelona, Spain from 26–28 March 2010 [9, 19].

Recruitment of consensus conference participants

The recruitment strategy for the consensus conference participants had to balance the need for international expertise without compromising a feasible decision-making process. Potential conference participants were selected from a pool of candidates interested in the project as well as from a pool of persons suggested by the project steering committee. Twenty-three experts in TBI participated in the consensus conference. There were nine physician participants: seven were specialists in Physical and Rehabilitation Medicine, one was a neurologist and one was a psychiatrist. Additionally, there was one nurse, six neuropsychologists, one speech therapist, one social worker, two physiotherapists and three occupational therapists. Sixteen participants were

Table I. Distribution of ICF categories across ICF components across preliminary studies.

	Systematic review	Expert survey	Cross-sectional study → empirical study	Focus group interview → qualitative study
Perspective	Literature	Experts	Clinicians	Clients
ICF component				
Body functions (*b*)	45 (39.8%)	44 (28.8%)	40 (27.6%)	44 (28.6%)
Body structures (*s*)	5 (4.4%)	20 (13.1%)	12 (8.3%)	13 (8.4%)
Activities and participation (*d*)	49 (43.4%)	54 (35.3%)	59 (40.7%)	59 (38.3%)
Environmental factors (*e*)	14 (12.4%)	35 (22.9%)	34 (23.4%)	38 (24.7%)
Total number of categories	113 (100%)	153 (100%)	145 (100%)	154 (100%)

Body functions, 'physiological functions of body systems including psychological functions'; *Body structures*, 'anatomical parts of the body such as organs, limbs, and their components'; *Activity*, 'execution of a task or action by an individual'; *Participation*, 'involvement in a life situation'; *Environmental factors*, 'physical, social and attitudinal environment in which people live and conduct their lives' [3].

from Europe (which included Turkey), four from the Americas (including South and North America) and three from Australia.

Iterative decision-making process

The ICF Core Set categories were identified in an iterative decision-making process with discussions and voting in working groups and plenary sessions. The participants were divided into three working groups, each containing seven-to-eight participants. One of the participants served as the working group (WG) leader who was responsible for facilitating discussion and the voting process. As with all of the participants, the WG leader had voting rights. The WG leader was supported by a non-voting, non-participating WG assistant, who documented the group results and the discussions. In the plenary sessions, WG leaders were given the opportunity to present their group decisions re ICF categories selected and discrepancies among the WG were debated. All participants were allowed to contribute to the discussion during the plenary sessions.

The decision-making process had two main aims: (1) selection of ICF categories for the Comprehensive ICF Core Set at the second-level, including the selection of categories that require further specification at lower hierarchical ICF levels (i.e. third and fourth level); and (2) selection of ICF categories from the Comprehensive ICF Core Set that should be included in the Brief ICF Core Set for TBI.

The categories for the Brief ICF Core Set for TBI were chosen from the Comprehensive ICF Core Set by means of a ranking exercise. The cut-off for the ranking was determined in a separate vote by the participants after the ranking was completed. Throughout the conference, the data resulting from the voting and ranking processes were continuously recorded using a database program specifically created for the development of ICF Core Sets. Details on the decision-making and consensus process can be requested from the ICF Research Branch (www.icf-research-branch.org).

Results

Preparatory studies

A selection of 183 ICF second level categories were extracted from the four preparatory studies: 113 from the literature review, 145 from the empirical study, 154 from the qualitative study and 153 from the expert survey. ICF categories that appeared in more than one preliminary study were counted only once in the list of 183 categories. See Table I for the distribution of ICF categories across the ICF components as well as across preliminary studies.

Comprehensive ICF core set

Following the series of votes, the total number of categories in the Comprehensive ICF Core Set was 139. With the exception of three categories, all categories related to the second level of the ICF. The 139 categories, which are presented in Table II, comprise 37 (27%) from the component *body functions*, two (1%) from *body structures*, 61 (44%) from *activities and participation* and 39 (28%) from *environmental factors*. Most of the *body functions* categories came from chapter 1 *Mental functions* (13 categories), followed by chapter 2 *Sensory functions and pain* and chapter 7 *Musculoskeletal functions*, both represented with seven categories.

The two categories from *body structures* are covered by chapter 1 *Structures of the nervous systems* and chapter 7 *Structures related to movement*.

All the chapters from *activities and participation* were represented in the Comprehensive ICF Core Set. Most of the *activities and participation* categories came from chapter 4 *Mobility* with 11 categories, chapter 1 *Learning and applying knowledge* and chapter 8 *Major life areas*, both with nine categories each.

Table II. List of categories included in the Comprehensive Core Sets.

ICF code	ICF category title
Body Functions (37)	
b110	Consciousness functions
b114	Orientation functions
b126	Temperament and personality functions
b130	Energy and drive functions*
b134	Sleep functions
b140	Attention functions*
b144	Memory functions*
b147	Psychomotor functions
b152	Emotional functions*
b156	Perceptual functions
b160	Thought functions
b164	Higher-level cognitive functions*
b167	Mental functions of language
b210	Seeing functions
b215	Functions of structures adjoining the eye
b235	Vestibular functions
b240	Sensations associated with hearing and vestibular function
b255	Smell function
b260	Proprioceptive function
b280	Sensation of pain
b310	Voice functions
b320	Articulation functions
b330	Fluency and rhythm of speech functions
b420	Blood pressure functions
b455	Exercise tolerance functions
b510	Ingestion functions
b525	Defecation functions
b555	Endocrine gland functions
b620	Urination functions
b640	Sexual functions
b710	Mobility of joint functions
b730	Muscle power functions
b735	Muscle tone functions
b755	Involuntary movement reaction functions
b760	Control of voluntary movement functions*
b765	Involuntary movement functions
b770	Gait pattern functions
Body Structures (2)	
s110	Structure of brain*
s710	Structure of head and neck region
Activities & Participation (63)	
d110	Watching
d115	Listening
d155	Acquiring skills
d160	Focusing attention
d163	Thinking
d166	Reading
d170	Writing
d175	Solving problems
d177	Making decisions
d210	Undertaking a single task
d220	Undertaking multiple tasks
d230	Carrying out daily routine*
d240	Handling stress and other psychological demands
d310	Communicating with (receiving) spoken messages
d315	Communicating with (receiving) non-verbal messages
d330	Speaking
d335	Producing non-verbal messages
d345	Writing messages
d350	Conversation*
d360	Using communication devices and techniques
d410	Changing basic body position
d415	Maintaining a body position
d420	Transferring oneself
d430	Lifting and carrying objects
d440	Fine hand use
d445	Hand and arm use
d450	Walking*
d455	Moving around
d465	Moving around using equipment
d470	Using transportation
d475	Driving
d510	Washing oneself
d520	Caring for body parts
d530	Toileting
d540	Dressing
d550	Eating
d560	Drinking
d570	Looking after one's health
d620	Acquisition of goods and services
d630	Preparing meals
d640	Doing housework
d660	Assisting others
d710	Basic interpersonal interactions
d720	Complex interpersonal interactions*
d730	Relating with strangers
d740	Formal relationships
d750	Informal social relationships
d760	Family relationships*
d770	Intimate relationships
d825	Vocational training
d830	Higher education
d840	Apprenticeship (work preparation)
d845	Acquiring, keeping and terminating a job*
d850	Remunerative employment
d855	Non-remunerative employment
d860	Basic economic transactions
d865	Complex economic transactions
d870	Economic self-sufficiency
d910	Community life
d920	Recreation and leisure*
d930	Religion and spirituality
Environmental Factors (41)	
e1100	Food
e1101	Drugs
e1108	Non-medicinal drugs and alcohol
e115	Products and technology for personal use in daily living*
e120	Products and technology for personal indoor and outdoor mobility and transportation*
e125	Products and technology for communication
e135	Products and technology for employment
e150	Design, construction and building products and technology of buildings for public use
e155	Design, construction and building products and technology of buildings for private use
e160	Products and technology of land development
e165	Assets
e210	Physical geography

(*continued*)

Table II. Continued.

ICF code	ICF category title
e250	Sound
e310	Immediate family*
e315	Extended family
e320	Friends*
e325	Acquaintances, peers, colleagues, neighbours and community members
e330	People in positions of authority
e340	Personal care providers and personal assistants
e355	Health professionals
e360	Other professionals
e410	Individual attitudes of immediate family members
e415	Individual attitudes of extended family members
e420	Individual attitudes of friends
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
e440	Individual attitudes of personal care providers and personal assistants
e450	Individual attitudes of health professionals
e455	Individual attitudes of other professionals
e460	Societal attitudes
e515	Architecture and construction services, systems and policies
e525	Housing services, systems and policies
e535	Communication services, systems and policies
e540	Transportation services, systems and policies
e550	Legal services, systems and policies
e570	Social security services, systems and policies*
e575	General social support services, systems and policies
e580	Health services, systems and policies*
e585	Education and training services, systems and policies
e590	Labour and employment services, systems and policies

With * are the ones included in the brief core sets.

The 39 categories from *environmental factors* comprise all five chapters of the ICF. Chapter 1 *Products and technology* and chapter 5 *Services, systems and policies* were represented by 11 and 10 categories, respectively.

Brief ICF core set

A total of 23 categories were included in the Brief ICF Core Set for TBI and are so asterisked in Table II. With the exception of Self-care (first or chapter level) the remainder of the categories were at the second-level. Eight categories came from *body functions*, one from *body structures*, eight from *activities and participation* and six from *environmental factors*.

While most of the categories from *body functions* came from chapter 1 *Mental functions*, the categories in *activities and participation* showed diversity in that they covered all but two of the chapters (chapter 1 *learning and applying knowledge* and chapter 6 *domestic life*).

With respect to environmental factors, the categories were evenly distributed, with two categories each in chapter 1 *Products and technology*, chapter 3 *Support and relationships* and chapter 5 *Services, systems and policies*.

Discussion

General

The formal consensus process that integrated evidence from the four preparatory studies and input from experts at the consensus conference led to the definition and formal adoption of the first version of the ICF Core Sets for TBI. The ICF Core Sets for TBI will allow clinicians and researchers to describe an individual's functioning using generally accepted multidisciplinary terminology [25, 26].

The Comprehensive ICF Core Set, containing 139 categories at the second level, aims to cover all aspects of functioning potentially relevant to individuals with TBI and may be useful for multidisciplinary assessments. The Brief ICF Core Set, containing 23 categories, is intended to be a minimal standard to describe functioning and may be used in a clinical setting or epidemiological studies [9, 27, 28].

One major issue discussed during the conference was the question of how to comprehensively cover the spectrum of changes after TBI in terms of body functions and structures, as well as in activity limitations and restriction in participation across the TBI recovery continuum. This issue was addressed by a presentation about one possible method for applying the ICF Core Sets for TBI in rehabilitation practice that follows the principles of the Rehab-Cycle [29].

The complexity of the scope of sequelae after TBI created a challenge to the expert panel during the consensus conference, since there was a need to select a sufficiently small number of categories to make the ICF Core Sets practical.

The ICF Core Sets for TBI are not health status measures but instead are a comprehensive, list of domains of functioning that are relevant for TBI and are intended as an international standard of *what* to measure and not *how* to measure. There is no intention to substitute existing measurement instruments with the ICF Core Sets for TBI, but rather to provide a framework for guiding comprehensive, multidisciplinary follow-up and treatment. Additionally, they can possibly be used to help determine the most appropriate instruments that best measure the problems experienced by the person with TBI [22].

Because the consequences of TBI include a wide spectrum of impairments, it is not surprising that the number of ICF categories is so large ($n = 139$). These results are consistent with other neurological conditions such as stroke in which the Comprehensive ICF Core Set comprises 130 categories [17, 30].

Body functions

Chapter 1 *Mental functions* is the ICF chapter that is widely represented in both the Comprehensive and the Brief ICF Core Sets, reflecting the need for a detailed description of mental problems by health professionals [28]. *Sensory functions and pain* and *Neuromusculoskeletal and movement-related functions* were also emphasized in the Comprehensive ICF Core Sets in addition to some categories related to voice and speech, cardiovascular and genitourinary functions [5].

After much discussion about including both *Psychomotor functions* (*b147*) and *Energy and drive* (*b130*) in the Brief ICF Core Sets, it was decided to include only *Energy and drive* in the interests of maintaining a brief core set because of the spectrum of behaviours that include craving, control of impulses and motivation that are more relevant for persons with TBI [31].

In contrast to the ICF Core Sets for stroke and neurological conditions in the acute stage [17, 30, 32] few categories from chapter 4 *Functions of the cardiovascular, hematological, immunological and respiratory systems* were included in the ICF Core Sets for TBI due to the lack of co-morbidities typical of young persons with TBI.

A number of ambiguities arose during the first round of voting, which were resolved in subsequent voting rounds. The two categories from chapter 4 *Blood pressure functions* (*b420*) and *Exercise tolerance functions* (*b455*) were intentionally included in the Comprehensive ICF Core Sets. The information gathered from the empirical study, expert survey and focus groups pointed toward inclusion in the ICF Core Sets due to the prevalence of post-TBI vasomotor impairments such as hypertension and postural hypotension and impairments in functions required for physical exertion. *Fatigability* (*b4552*), covered under *Exercise tolerance functions* (*b 455*) is one of the most common problems identified by persons with TBI during the focus groups.

Similarly, *Thought functions* (*b160*) was also considered as ambiguous during the first round of voting. Ultimately, however, it was included in the Comprehensive ICF Core Set, because it refers to functions related to the process of creating new ideas including aspects commonly described by neuropsychologists such as speed of processing, conceptualization of ideas and coherence and logic of the thinking process.

Another topic of debate concerned *Sexual functions* (*b640*) and *Intimate relationships* (*d770*) that were seen as possible overlapping categories. While there was 100% agreement for including *Intimate relationships* (*d760*), the participants questioned whether to also include *Sexual functions*. After much discussion, it was decided that both categories should be included in the Comprehensive ICF Core Sets for TBI with the argument that *Sexual functions* concerned the physiological aspects of sexual activity, whereas *Intimate relationships* has its focus in creating and maintaining a close relationship between sexual partners.

Body structures

In contrast, *body structures* was described with comparatively few categories. Although there was complete agreement in selecting *Structure of brain* (*s110*), there was a debate whether to include *Structure of head and neck region* (*s710*) and *Structure of shoulder region* (*s720*). The experts decided to include *s710*, because there was greater representation of the head and neck region in the preliminary studies than *s720*. Additionally, the structure of the shoulder region was considered less important since the categories describing its impact on daily life activities, such as dressing or pain, were already included in *activities and participation*.

Activities and participation

Limitations and restrictions in this domain appeared to be critically important to patients with TBI, as reflected by the fact that the majority of the categories included in the Comprehensive ICF Core Set came from *activities and participation* [33, 34]. All the chapters of *activities and participation* are represented in the ICF Core Sets for TBI, indicating that TBI potentially imparts a wide effect on patients' daily living. From the 69 categories of *activities and participation* that were selected in the preliminary studies, 61 categories were chosen for the Comprehensive ICF Core Set. *Mobility*, *Learning and applying knowledge*, *Major life areas* and *Self-care* are all key issues for patients after TBI.

Learning to read (*d140*), *Learning to write* (*d145*) and *Learning to calculate* (*d150*) were excluded during the first round of voting. Even though some people justified their inclusion because they are common strategies used in rehabilitation, the final consensus was that the categories *Reading* (*d166*), *Writing* (*d170*), *Acquiring skills* (*d155*) as well as *Solving problems* (*d175*) may best define the characteristics of a patient with TBI.

One of the greatest challenges during the consensus conference was selecting as few of the Comprehensive ICF Core Set categories as possible to incorporate in the Brief Core Sets. The seven Comprehensive ICF Core Set categories of *Self-care* is an example of the difficulty in deciding on specific categories to be included or excluded. Due to the fact that the difficulties in self-care experienced by patients with TBI are so encompassing, all seven categories as represented by the chapter d5 *Self-Care* were chosen for inclusion in the Brief ICF Core Set. With this chapter, caring for oneself, washing and drying oneself, caring for one's body and body parts, dressing, eating and drinking and looking after one's health were covered.

The large number of categories from *activities and participation* compared to *body functions* suggests that clinical findings alone are not good predictors of global functioning and health status of persons after a TBI.

Environmental factors

Regarding environmental factors there was general agreement that support provided by Immediate and Extended family (*e310*, *e315*), Friends (*e320*), People in positions of authority (*e330*), Personal care providers and personal assistants (*e340*) as well as Health professionals (*e355*) have a considerable impact on the functioning of people with TBI.

Study limitations

The participants of the consensus conference exclusively comprised health professionals working with patients with TBI; therefore, the only representation of patients was based on the focus groups and personal interviews. This may limit the applicability of the ICF Core Sets for TBI in highly patient-centred treatment approaches. Furthermore, the majority of participants came from industrialized countries; as a consequence the perspective of professionals in developing countries may not be sufficiently considered in the ICF Core Sets for TBI.

Conclusion

The ICF Core Sets for TBI are the starting point for operationalizing the ICF in planning interventions for patients with TBI. At an individual level, ICF Core Sets can be used to describe the patient's functioning and to define rehabilitation goals. At an institutional and policy level, ICF data can serve as an additional source of information for resource distribution and, consequentially, optimization of the rehabilitation process.

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6. Resumen de resultados

a. What domains of the International Classification of Functioning, Disability and Health are covered by the most commonly used measurement instruments in traumatic brain injury research?

Se realizó una búsqueda sistematizada de la literatura centrada en estudios con pacientes con traumatismos craneoencefálicos empleando las bases de datos de Medline, Embase y psychINFO. Se analizaron los 193 manuscritos que reunían los criterios de inclusión.

En estas publicaciones se encontraron doscientos ochenta y tres instrumentos de medida. Por estar presentes en más del 20% de las publicaciones, la *Functional Independence Measurement (FIM),* la *Glasgow Outcome Scale (GOS),* la *Disability Rating Scale (DRS),* la *Wechsler Adult Intelligence Scale (WAIS),* el *Trail Making Test (TMT)* y la *Community Integration Questionnaire (CIQ)* fueron seleccionadas.

Para realizar el análisis conceptual, se empleó una técnica de traducción basada en las *"linking rules"* de A. Cieza(Alarcos Cieza et al. 2005). Estas reglas consisten en que a cada unidad dotada de un significado conceptual, se le debe de adjudicar el código de la CIF más apropiado. Por ejemplo, si en una escala hay un ítem que evalúa cómo se viste una persona, se identifica el concepto "vestirse" y se le adjudica el código d540 que significa "habilidad para vestirse".

Cada uno de los ítems avaluados en las escalas anteriormente mencionadas fue analizado para la identificación de los conceptos y se tradujeron a 212 códigos de la CIF. Para garantizar el consenso de la traducción, ésta fue realizada por dos codificadores independientes y la congruencia de los resultados fue analizada mediante el análisis estadístico kappa mostrando un coeficiente de consenso de 0.83 lo que significa un acuerdo bueno.

Un 73% (n= 154) de los conceptos encontrados se referían al dominio de *actividades y participación*, un 24% (n= 51) pertenecía al dominio de *funciones corporales* mientras que un 3% (n=7) a *factores medioambientales.* La mayoría de los ítems de las *funciones corporales* se encontraban en los capítulos de *funciones* *mentales* y *músculo esqueléticas* y eran capturados por la DRS y los test neuropsicológicos. La FIM y la CIQ se centraban en el dominio de *actividades y participación.* La primera de ellas con una implicación en el constructo de *actividad* como lo son aspectos de movilidad, de autocuidado y comunicación, mientras que la CIQ se centra en el constructo de *participación* en relación al retorno al trabajo habitual, vida doméstica así como también la inmersión en las relaciones interpersonales y sociales. Los factores medioambientales apenas han sido descritos y destaca la práctica ausencia de cuestionarios que evalúen la calidad de vida en TCE.

b. ICF use to identify common problems on a TBI neurorehabilitation unit in Spain.

Se realizó un estudio transversal prospectivo de localización en una unidad de neurorrehabilitación. Se incluyeron a pacientes que habían sufrido un TCE y que dieron su consentimiento para participar en la entrevista.

Un total de 103 pacientes participaron en el estudio y se recogieron datos demográficos y relacionados con su lesión así. También se les administraron varios cuestionarios sobre calidad de vida y comorbilidad. Para evaluar su funcionalidad se empleó un subconjunto de dominios de la CIF conocido como la ICF checklist 2.1 que consiste en un extracto simplificado de las más de 1000 categorías de la CIF.

Los pacientes evaluados seguían el patrón clásico de un TCE en una población joven (34 años), con predominio de varones (83/20), solteros, con un nivel de educación medio y que sufrieron un TCE como consecuencia de un accidente de tráfico.

La mayoría de los pacientes había sufrido un TCE grave, entendiendo por ello una puntuación en el momento del accidente inferior a 5 según la Glasgow Coma Scale

El estado general evaluado por el Comorbidity Questionnaire evidenciaba un buen estado de salud, tanto en pacientes evaluados en una fase crónica como en pacientes agudos hospitalizados en una planta de neurorehabilitación. Se administró el EQ5D para evaluar la percepción de salud que tenían los participantes y el WHOQOL para evaluar la sensación subjetiva de calidad de vida. Ambos cuestionarios mostraron que los pacientes estaban insatisfechos con su habilidad en la realización todas las actividades de la vida diaria.

En relación a las *funciones corporales* que se describían como más alteradas destacan las funciones superiores (b164), el estado de ánimo (b152) y las funciones relacionadas con la energía e impulsos (b130). La fuerza (b730) así como problemas en el tono muscular (b735) y la movilidad de las articulaciones (b710) también constituían las categorías con una afectación en más del 50% de los pacientes.

En relación a las *estructuras corporales* se reportaron cambios en la estructura del cerebro, en el hombro y extremidad superior, pelvis y extremidad inferior.

En cuanto al dominio de *actividad y participación* todos los capítulos se encontraban alterados y siete de nueve tenían al menos alguna categoría de la CIF que significaban un problema para más del 80% de los pacientes como por ejemplo la realización de actividades generales (d2), movilidad (d4), vida doméstica (d6) y áreas principales de la vida (d8) tales como llevar a cabo las tareas y acciones necesarias para participar en las actividades educativas, en el trabajo, en el empleo y en las actividades económicas.

Muchos de los problemas detectados en el dominio de funciones corporales como la espasticidad o la pérdida de fuerza, y del dominio de actividades y participación como el aprendizaje, la movilidad y el autocuidado suelen tratarse de forma rutinaria en centros específicos de rehabilitación, pero otros como la independencia económica, el retorno al trabajo o las relaciones familiares y sociales es posible que precisen de un mayor abordaje, sobretodo en fases más subagudas cuando los pacientes retornan a su domicilio.

En la comparación del perfil de funcionamiento entre pacientes ingresados y pacientes en fase crónica, las diferencias más significativas se detectaron predominantemente en el dominio de actividades y participación.

Los *factores medioambientales* fueron descritos fundamentalmente como facilitadores, en especial la familia (e110) y los profesionales de la salud (e355). Las actitudes sociales (e460) y las normas (e465) fueron nombradas como barreras.

La investigación sobre el impacto de estos factores medioambientales fundamentado en la CIF puede contribuir a una mejor conceptualización de las intervenciones necesarias en rehabilitación durante la fase aguda, subaguda y crónica y, al mismo tiempo este marco ayuda a conjugar la visión del profesional con las necesidades del propio paciente.

c. ICF profiling of patients with traumatic brain injury: an international professional survey.

En condiciones ideales el manejo y tratamiento de las secuelas de un TCE debe realizarse por un equipo multidisciplinar y constituido por diferentes profesionales entre los que cabe incluir a especialistas médicos como rehabilitadores, neurólogos psiquiatras, neurocirujanos, traumatólogos, personal de enfermería, fisioterapia, terapeutas ocupacionales, neuropsicólogos, ortopedas, trabajadores sociales….

El poder obtener la perspectiva de cada uno de los profesionales que tratan a un mismo paciente tiene un beneficio directo a la hora de describir cuál es su espectro funcional.

En este trabajo, ciento treinta y siete profesionales de las diferentes regiones de la OMS fueron entrevistados y de sus respuestas se aislaron 5656 conceptos, de los cuales un 92.66% pudieron ser traducidos a la CIF. Un 33.03% fueron vinculados al dominio de *funciones corporale*s, un 27.28% al dominio *de actividades y participación*, un 10.98% al dominio de *estructuras corporales* y un 21.38% al *de factores medioambientales*. La gran variedad de categorías identificadas y su distribución a lo largo de todos los dominios y capítulos de la CIF, puso de manifiesto nuevamente la complejidad de secuelas y afectación funcional del TCE. El uso de la CIF sirvió además para comparar las diferentes visiones en los diferentes tipos de profesionales de la salud que reflejan las características típicas de sus competencias. Así los neuropsicólogos y logopedas tendían a centrarse en aspectos de comunicación y de funciones superiores, los trabajadores sociales en el ámbito social mientras que médicos y fisioterapeutas tendían a aportar una visión más global.

Otra de la importancia de este trabajo fue la inclusión de profesionales sanitarios de las diferentes regiones de la OMS, lo que sirvió para ampliar la visión a personas que viven en otras culturas y en circunstancias diferentes, conociendo así una experiencia más globalizadora.

d. Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups

Con la intención de evaluar la perspectiva de los pacientes que habían sufrido un TCE, se realizaron seis grupos focales con un total de 17 participantes. Nueve mujeres y ocho hombres con edades comprendidas entre los 22 y los 55 años que habían sufrido un TCE leve y en el contexto de un programa de rehabilitación ambulatoria fueron sometidos a estudio.

El motivo de la introducción de este tipo de estudio cualitativo fue el de poder capturar mejor la perspectiva de aquellos que sufrieron un TCE. Los estudios cualitativos, a diferencia de los cuantitativos permiten al paciente, mediante el uso de preguntas abiertas, la descripción de cómo la patología le afecta empleando sus propias palabras.

Las entrevistas fueron realizadas por personal del equipo siguiendo un guion basado en los dominios del modelo biopsicosocial que incluía tres preguntas:

1. Si piensa en su cuerpo y su mente, ¿Cuáles son las partes de su cuerpo o de su mente que no funcionan o que no están como debieran?
2. Si piensa en su vida diaria, ¿cuáles son los problemas a los que se enfrenta habitualmente como consecuencia de su lesión?
3. Si piensa en aquellas condiciones del entorno en donde vive, ¿Cuáles considera que son aquellas cosas que le facilitan su vida o que por el contrario le entorpecen?

Las entrevistas duraron aproximadamente una hora y fueron grabadas. Así, las respuestas de los participantes fueron debidamente analizadas y las ideas destacables fueron traducidas mediante las *linking rules* a la CIF.

Se recogieron un total de 881 conceptos dotados de significado, de los cuales se detectaron 99 categorías de segundo nivel de la CIF. De ellas, un total de 41 categorías fueron reportadas por los participantes con una frecuencia alta o moderada y las 58 restantes con una baja categoría.

En relación a las *funciones corporales*, 30 categorías de un total de 99 que emergieron describían problemas relacionados con la energía e impulsos (b 130), funciones de memoria (b144), funciones emocionales (b152), funciones superiores (b164) y funciones de atención (b140). En relación al dominio de actividades y participación 39 categorías evidenciaban un problema considerable en la realización de tareas y rutinas diarias (d230), trabajo y empleo (d850), cuidar de uno mismo (d570) , mantener relaciones con los amigos (d750) y sobrellevar el estrés (d 240).

Un total de 27 categorías relacionadas con los *factores medioambientales* emergieron como fenómenos influyentes, tales como el soporte proporcionado por los profesionales sanitarios (e355), los servicios de salud y la seguridad social (e580). Las actitudes manifiestas por los amigos u otros miembros de la comunidad también aparecen reflejados como factores que afectaban la percepción del estado de salud.

El estudio ofrece una visión global del proceso que vive una población sana que ha padecido un TCE. Aun tratándose de un TCE leve, los problemas cognitivos y emocionales tienen un impacto notable en la realización de actividades de la vida diaria y en la participación en aquellas circunstancias que sería consideradas como normales para su edad.

e. Development of the International Classification of Functioning, Disability and Health core sets for traumatic brain injury: an International consensus

Este manuscrito tenía como intención recoger la información emitida por un conjunto de expertos en el mundo de la rehabilitación del TCE, obtenida a través de un ejercicio Delphi y decidir qué categorías de la CIF son las más representativas en una población con secuelas de un TCE.

La metodología Delphi consiste en un ejercicio de toma de decisiones en el que un grupo de expertos distribuidos en pequeños subgrupos debaten sobre un tema y consensuan unos determinados criterios. El punto de partida del debate consistió en la presentación de los datos obtenidos a través de estudios realizados con anterioridad para así poder capturar las diferentes perspectivas de los actores involucrados en el proceso de rehabilitación del TCE, esto es, la perspectiva del profesional, del investigador, del paciente y la observación clínica real:

-*Perspectiva del paciente*: recogida a través de un estudio cualitativo consistente en la realización de 14 grupos focales y cuatro entrevistas personales.

-*Perspectiva del profesional de la salud* que incluyó una entrevista a 107 profesionales de 55 diferentes países en las seis regiones de la OMS.

-*Perspectiva de los investigadores* fue recogida mediante la revisión de la literatura y la traducción de los conceptos asesorados en la misma a los códigos de la CIF.

-*Perspectiva clínica* mediante la aplicación de la checklist de la CIF a 500 pacientes procedentes de Noruega, Australia, España e Italia.

Se hizo una preselección de categorías basadas en la CIF para proceder a la votación por profesionales de la salud implicados en el TCE.

Se seleccionaron a 23 profesionales de un conjunto de posibles candidatos que fueron nombrados por las distintas asociaciones y colegios profesionales tratando de buscar una homogeneidad en términos de regiones de la OMS y de disciplinas sanitarias.

Los participantes se dividieron en tres grupos y se estableció un proceso de toma de decisiones siguiendo las recomendaciones del "Nominal Group Technique"(Delbecq, A., A. Van de Ven, and D. Gustofon 1975)

El punto de partida del proceso de votación fue un panel con 183 categorías de segundo nivel, 113 categorías recogidas de la revisión de la literatura, 145 de la revisión del estudio empírico, 154 del estudio cualitativo y 153 de la entrevista al profesional.

Tras la votación, se decidieron que un total de 139 categorías constituirían los *Comprehensive Core Sets* para el TCE, es decir el conjunto mínimo integral de categorías del total de la CIF que pueden describir el espectro funcional de un paciente con TCE. Por el contrario, se escogieron 23 categorías para describir los *Brief ICF Core Sets*, como aquel conjunto mínimo breve de datos necesarios para describir el espectro funcional en ámbitos en donde fuese necesaria una descripción más concisa como puede ser en el encuentro clínico o en la realización de estudios epidemiológicos.

7. Discusión

Instrumentos de medida en el TCE

> *"To measure is to know,*
> *if you cannot measure you*
> *will never be able to know more"*
> *Lord Kelvin*

La complejidad de las secuelas tras un TCE y su repercusión funcional se pone de manifiesto en la existencia de un gran número de instrumentos de medida encontrados en la revisión de la literatura. Cuando una persona sufre un traumatismo se produce inicialmente una alteración en alguna estructura corporal o en alguna función corporal que en mayor o menor medida alterará el dominio de *actividad y participación*. La recuperación del buen funcionamiento de ambas no siempre es posible y consecuentemente se producirán déficits que alteren el funcionamiento y la vida de una persona. John Whyte manifiesta que el principal objetivo de la rehabilitación es disminuir la discapacidad(John Whyte & Barrett 2012) buscando aminorar las secuelas producidas por un traumatismo, pero, ¿cómo se puede medir un concepto tan abstracto como las consecuencias de un TCE? En otras disciplinas médicas que tratan patologías como el cáncer, la hipertensión o diabetes, la investigación en resultados se centra en la medida de la función o estructura. Este paradigma médico no es aplicable al ámbito de la rehabilitación neurológica ya que ésta precisa de un modelo más complejo debido a la enorme interrelación y dependencia entre la esfera física, cognitiva y conductual. Además, la rehabilitación neurológica presenta otra particularidad y es el hecho del cambio de funcionamiento a lo largo del tiempo y el cambio tanto en las perspectivas y en los objetivos de rehabilitación en los pacientes como en los profesionales médicos. El hallazgo de numerosos instrumentos de medida empleados en estudios con pacientes con TCE traduce precisamente esta consigna.

Evidentemente la selección del instrumento de medida corre a la par que el objetivo particular del estudio, condición necesaria para evaluar un aspecto concreto, pero también motivo de limitación para la comparación entre diferentes estudios, centros o países. La mayoría de los instrumentos identificados en este trabajo poseen unas buenas propiedades psicométricas y todos ellos, en conjunto, cubren una amplia área de funcionamiento (Bagiella et al. 2010). La literatura científica publicada hasta el momento ha proporcionado escasa información sobre qué instrumentos son los más apropiados para cada situación clínica o de investigación por lo que recientemente se está produciendo un incremento de publicaciones científicas que hacen referencia al análisis conceptual de diferentes escalas empleando el marco de la CIF de referencia para su comparación (Koskinen et al. 2011; Salter et al. 2011)(Potter et al. 2011; Bagiella et al. 2010; Nichol et al. 2011; Wilde, Whiteneck, et al. 2010; Wilde, McCauley, et al. 2010; van Baalen et al. 2006; Shukla et al. 2011).

Siguiendo el modelo biopsicosocial de la OMS y empleando las clasificación internacional de la funcionalidad como marco conceptual, los instrumentos de medida hallados en la revisión se podrían distribuir según los dominios de la CIF, en aquellos orientados a determinar un déficit, como los test neuropsicológicos, a determinar limitación en las actividades como el FIM, la restricción en la participación como el CIQ.

Como mencionó Scarponi(Scarponi et al. 2009), la CIF es un instrumento flexible para monitorizar los resultados y definir los objetivos de la rehabilitación. En este estudio se ha apreciado que la CIF cubrió de forma adecuada los ítems de los instrumentos evaluados permitiendo la comparación conceptual entre las diferentes escalas. La mayoría de las escalas se centraron en la evaluación de conceptos englobados dentro del dominio de *actividades y participación* lo que se justifica porque la rehabilitación fundamentalmente trata de mejorar estos aspectos como también se describe en los trabajos de Hart, Sveen, Brütt, y Sander(Fleming et al. 2011; Unni Sveen et al. 2008; Brütt et al. 2013; Hart et al. 2010; Sander et al. 2012)

La búsqueda destaca la escasez de escalas que evalúen el impacto del TCE o la calidad de vida.

Evidentemente, uno de los retos a los que se enfrentan los instrumentos de calidad de vida en la población de TCE es la fiabilidad de las declaraciones de los propios pacientes con problemas cognitivos y de comunicación que pueden comprometer la validez de sus propias puntuaciones. Por la propia idiosincrasia del TCE se ha demostrado en estudios previos, la llamada paradoja de la discapacidad: la población de TCE con una mayor discapacidad tiene una tendencia a puntuar mejor en escalas de calidad de vida que aquellos que funcionalmente están mejor (Albrecht & Devlieger 1999).(Sasse et al. 2012)

Alteraciones en las funciones y estructuras corporales

> *"To be or not to be"*
> *Shakespeare*

Tras la fase aguda de hospitalización y de cuidados intensivos, el paciente que ha sufrido un TCE puede seguir presentando unas secuelas que afecten tanto a las estructuras corporales como a las funciones. Los problemas, tal y como se detallaron en la introducción de esta tesis pueden ser extensos lo que traduce la necesidad de un tratamiento complejo con un abordaje interdisciplinar y un enfoque integral en el proceso de rehabilitación (Doig et al. 2010; Doig et al. 2010; Rudi Coetzer 2008).

El estudio empírico permite ver el impacto del TCE con una especial preponderancia sobre los capítulos de funciones mentales y funciones musculoesqueléticas. Esta afirmación, que tal vez pueda parecer redundante para quienes conozcan la idiosincrasia de esta patología, es interesante desde un punto de vista taxonómico. Por ejemplo, a priori, se podría pensar en que las necesidades de un servicio médico que trate a una población con TCE puedan ser similares a una que trate el ictus. Sin embargo el perfil descrito por esta taxonomía es totalmente diferente en ambas poblaciones, ya que la afectación del ictus en materia de funciones y estructuras corporales es más complejo que el TCE por la típica comorbilidad asociada a la enfermedad cardiovascular. Adicionalmente, los problemas conductuales asociados al ictus parecen tener un menor impacto en el dominio de actividades y participación, probablemente porque la edad de incidencia es en una población mayor(Geyh et al. 2004; Algurén et al. 2012). La clasificación taxonómica del espectro funcional fundamentado en la CIF facilita la comparación de datos con otras patologías. Así se puede encontrar en un estudio recientemente publicado por un grupo australiano en donde investigan la afectación funcional de las secuelas producidas por tumores cerebrales y encuentran que el espectro funcional se asemeja más al TCE que al ictus(Khan & Amatya 2013; Khan et al. 2010).

Dentro de las funciones intelectuales, el estudio empírico evidenció una afectación importante típicamente descrita por los tests neuropsicológicos como son la velocidad de procesado de la información (b160) o problemas de atención (b140) y memoria (b144), pero también problemas en la energía y fatiga (b130), que al ser síntomas más subjetivos, muchas veces no son evidenciables en una consulta clínica y que tal vez el paciente por la propia idiosincrasia del TCE no se decida a comentar a su médico (Belmont et al. 2009; J. L. Ponsford et al. 2013; Cantor et al. 2013).

El estudio empírico ofrece también la posibilidad de ver diferencias en el grado de afectación de la población en la fase aguda en relación a una fase más crónica y su relación con la calidad de vida. Esto concuerda con la evolución natural de esta patología, sobre todo en aquellas funciones que están relacionadas con aspectos motores. Las funciones relacionadas con aspectos cognitivos, aunque suelen mejorar a un ritmo más lento que recuperación motriz, son, sin embargo las mayores responsables de los problemas de integración social y laboral, y por tanto se correlacionan más con la calidad de vida (N Andelic et al. 2009; Hanks et al. 2013; Jacobsson et al. 2009).(Juan Carlos Arango-Lasprilla et al. 2012)

En el estudio de grupos focales, los pacientes examinados describieron 30 categorías de *funciones corporales* y 3 de *estructuras corporales* como déficits personalmente importantes en su día a día destacando nuevamente la fatiga, la atención, la memoria, las funciones superiores y el estado del ánimo como aquellas funciones que más perturbación ocasionaban en su correcto funcionamiento.

Hay cuatro categorías de este dominio de *funciones corporales* que son mencionadas por el estudio de A Cieza(Alarcos Cieza et al. 2013) como responsables, entre otras, de la variabilidad de los cambios a corto plazo de los resultados en enfermedades neurológicas como el TCE, el ictus, la enfermedad de Parkinson, la depresión, el trastorno bipolar o la esclerosis múltiple. Problemas en la energía (b130), en las funciones emocionales (b152) , el sueño (b134) y el dolor (b280) se asocian según Cieza a una peor sensación subjetiva del estado de salud. Estas categorías comunes a esas patologías aparecen descritas tanto en el estudio empírico como en el estudio de grupos focales y son recogidas por los *Core Sets*. En la entrevista al profesional también aparecieron todas con la excepción del sueño.

En la entrevista al profesional, que incluía profesionales de la salud típicamente constituyentes del equipo de rehabilitación multidisciplinar, destacó por mencionar el mayor número de alteraciones en los dominios de *funciones y estructuras corporales*. Un 44.01% de las categorías identificadas por los profesionales que tratan a pacientes con TCE estaban dentro de esos dominios, lo que indica que el paradigma del modelo médico aún está muy presente en la mentalidad de los profesionales. Obviamente si se piensa en un médico, es lógico pensar que éste centre sus preocupaciones hacia la mejoría de las funciones de su paciente y que un terapeuta ocupacional dirigiese su atención hacia la mejoría de actividades de la vida diaria o actividades vocacionales.

Este hallazgo supone un decalaje conceptual entre el "ser" y el "hacer", es decir cúales son las funciones corporales que tiene preservadas el paciente y cuál es la realidad que le permite hacer las actividades que se considerarían típicas en él. El profesional entrevistado, independientemente de su condición y profesión, ha demostrado tener más presente el dominio de las *funciones corporales* en vez del dominio de *actividades y participación,* siendo un indicador indirecto de la herencia del modelo médico tradicional de la discapacidad en detrimento de una visión más holística de la misma como sería el modelo bio psico social.

Actividades y Participación

> *"Un hombre no es otra cosa que lo que hacer de sí mismo".*
>
> *Jean Paul Sartre*

Las limitaciones en la actividad y la restricción en la participación parecen ser las áreas más relevantes en cuanto al funcionamiento tras un TCE y la literatura científica acierta a señalarlas como responsables del impacto morboso que el TCE tiene sobre la persona, la familia y la sociedad (Unni Sveen et al. 2008; Fleming et al. 2011; Sander et al. 2012; van der Mei et al. 2011; F. V. Wright et al. 2008). Todas las áreas del dominio de *actividades y participación* se encontraban alteradas y de forma específica las *áreas principales de la vida,* tales como la educación, el trabajo y la independencia económica así como las *áreas de la vida comunitaria, social y cívica* que fueron referidas por los pacientes con el calificador de 4, lo que significa un problema muy importante. En una población joven y con toda una vida por delante, la imposibilidad de retornar al trabajo constituye una de las peores consecuencias del TCE conllevando a una alteración en la calidad de vida. Llama la atención que en estudios similares, el capítulo de la *vida comunitaria* es referido como problemática por nuestra muestra de forma mucho más consistente que la muestra de Koskinen y Aiachini (Koskinen et al. 2007; Aiachini et al. 2010). Esta diferencia se podría justificar por el carácter retrospectivo de la muestra finlandesa y de las diferencias culturales en el estudio de Aiachini.

Volviendo nuevamente al impacto morboso del TCE sobre el retorno al trabajo, se observó en el estudio empírico que un 89% de la muestra refería no estar trabajando. Un 75% de los pacientes entrevistados en Noruega también referían la misma problemática a pesar de que el grupo noruego tenía una lesión de base menor que la del estudio empírico pero estos hallazgos concuerdan con la literatura preexistente(Jourdan et al. 2013). (Radford et al. 2013). El hallazgo de una alta incidencia de pacientes sin trabajo remunerado en la fase crónica durante el estudio empírico y que concuerda con el relato de los propios pacientes en el estudio de grupos focales podría constituir una advertencia significativa para los gestores de salud y promotores de políticas sanitarias a modo de inversión en una fase subaguda o crónica del curso de la patología, en donde la mejoría en la función o estructura no es esperable pero sí la facilitación del desempeño de la participación en una actividad laboral. Existen estudios que demuestran que la inclusión en programas específicos favorece la promoción y realización de actividades remuneradas lo que significa que la inversión en programas específicos de retorno al trabajo puede ser más efectiva que la rehabilitación convencional en ciertos períodos de la evolución natural tras un TCE

A lo largo de los diferentes trabajos que constituyen esta tesis doctoral se describe el impacto negativo sobre actividades y participación que tienen las alteraciones en las funciones superiores y esto ha sido el denominador común reportado por los participantes en esta entrevista. Pero dentro de la afectación de las *funciones mentales*, los problemas en la conducta como la falta de iniciativa, la apatía, la baja tolerancia a la frustración o la irritabilidad son, con probabilidad, las características más salientables en aquellos pacientes que a pesar de tener una buena evolución física manifiestan problemas en los dominios de la *participación* en la sociedad. He aquí el punto en común que en ocasiones una patología orgánica como el TCE puede tener con otras patologías de índole mental como los trastornos de personalidad.

En este sentido, no resultó extraño durante la realización del estudio de entrevista al profesional en donde sobretodo los fisioterapeutas manifestaban la frecuencia con la que en numerosas ocasiones el trabajo típico de fisioterapia era interferido por problemas conductuales pero también por déficits de atención, de memoria y otros déficits cognitivos.

Factores Medioambientales

"Yo soy yo y mis circunstancias"
Ortega y Gasset

En 1914 Ortega y Gasset publicó la célebre frase en Meditaciones del Quijote de "*Yo soy yo y mis circunstancias, si no la salvo a ella, no me salvo yo"*. Casi 100 años más tarde la investigación ha proveído de numerosos estudios que proporcionan información de cómo el medio ambiente influye en nuestro "ser". Esta influencia se manifiesta desde la activación de ciertos genes, oncogenes pero también es conocido como el entorno influye en el desarrollo de nuestra personalidad o la potenciación de nuestra inteligencia… Es lógico por ello pensar el impacto que el entorno puede tener sobre una patología tan vaga y diversa como el TCE.

Los factores medioambientales pueden tener un impacto tanto positivo como negativo sobre el funcionamiento. En el estudio empírico la mayoría de pacientes coincidió en atribuir un impacto positivo al apoyo de la familia y de los profesionales sanitarios. Un 90% de los pacientes refirió que la familia constituía un apoyo importante y de hecho la mayoría residían con su familia. Pero al mismo tiempo también mostraron la existencia de problemas en las relaciones familiares. Estos resultados son consistentes con la literatura y con otras patologías neurológicas como el ictus(Geyh et al. 2004). La falta de independencia y la necesidad de supervisión de la familia ocasionalmente pueden aparentar un problema en pacientes con escasa capacidad de percepción de sus déficits y de sus problemas(Sander et al. 2012; Wolters Gregório et al. 2011; Nonterah et al. 2013; Jeffrey S Kreutzer et al. 2010) .

De hecho, en nuestro estudio se ha podido ver cómo el grupo de pacientes en fase crónica reportaban un mayor número de problemas en la categoría d760 (relación con la familia) en relación a los pacientes agudos. Esto es consistente con la naturaleza de recuperación del TCE (Jacobsson et al. 2009)(N Andelic et al. 2009). Los pacientes tienden a experimentar una mejora en las funciones físicas pero los problemas cognitivos van a otra velocidad y no es raro que en ocasiones las relaciones familiares empeoren a lo largo del tiempo(D. S. Brown & Nell 1992; J. Ponsford et al. 2003) .

Las actitudes de los amigos y de la sociedad manifestaban una tendencia a actuar como barreras, tanto en el estudio empírico como en el de grupos focales. Este hecho es ampliamente conocidos por los clínicos, que con frecuencia escuchan como los pacientes relatan la pérdida de amistades previas, refieren dificultades en hacer nuevas amistades e iniciar relaciones amorosas e incluso cómo en ocasiones tienen la sensación de que los otros les miran "*como si tuviesen un retraso mental*". Una revisión de la literatura publicada en el 2013 concluye que la mayoría de los estudios publicados entre 2011 y 2012 manifiestan que las personas que han sufrido un traumatismo craneoencefálico están sujetas a una discriminación y a un estigma social (Ralph & Derbyshire 2013). Otro estudio publicado por Simpson y cols y centrado en una población con secuelas por TCE en tres países diferentes (Italia, Líbano y Vietnam) encontró que a pesar de las diferencias culturales, las tres poblaciones estaban sujetas a un estigma y aislamiento social (Simpson et al. 2000).

El apoyo de los profesionales de la salud también fue manifestado como un vector facilitador por la mayoría de pacientes y esto concuerda con las estadísticas publicadas por el Ministerio de Sanidad, Servicios Sociales e Igualdad (MSSSI s. f.). En el estudio de grupos focales sin embargo, los facilitadores se centraron más en los profesionales y los servicios de salud y de seguridad social siendo estos dos últimos referidos como factores con impacto negativo en el estudio realizado en Barcelona. Este hecho diferencial puede justificarse al tener en cuenta que el estudio empírico se basó en una población española mientras que el estudio cualitativo era una población noruega. Aunque el manuscrito aún no ha sido publicado, los datos obtenidos de un estudio con grupos focales realizado en Barcelona eran consistentes con los hallazgos del primero y no sería extraña la existencia de una relación entre los hábitos culturales de cada población y el impacto sobre la percepción de salud y discapacidad.

Los profesionales de salud son conscientes del impacto de los factores contextuales y un 21.8% de sus respuestas de la encuesta fueron vinculadas a este dominio. Aun así cabe destacar que la mayoría de los instrumentos de medida empleados por los profesionales no se dirigen de forma hacia la evaluación de los factores medioambientales. Esto es un factor a tener en cuenta, ya que a medio y a largo plazo, una vez que las secuelas de una patología están estabilizadas, los factores medioambientales son los que mayor impacto tienen sobre la calidad de vida y la percepción subjetiva de salud (Algurén et al. 2012; Tempest et al. 2012)(Jeyaraj et al. 2013) . En este sentido son interesantes las conclusiones del estudio de Helene Lefebre en donde detectaba como factores predisponentes a una sensación subjetiva de peor calidad asistencial y determinante del encuentro médico paciente, la falta de información, el soporte emocional y financiero pero también el hecho de disponer de ayudas y asesoramiento sobre servicios a largo plazo (H Lefebvre et al. 2005; Hélène Lefebvre & M.-J. Levert 2012).

Desarrollo de los TBI ICF Core Sets

El objetivo final de este proyecto era definir el conjunto de categorías de la CIF que describiesen de una forma integral y en un lenguaje neutral el espectro funcional de los pacientes que hubieran sufrido un TCE. La selección de estas categorías se fundamentó en la decisión de un grupo de expertos de diferentes partes del mundo y se basó en la evidencia recogida por los estudios previamente realizados. Así, la perspectiva del investigador, del paciente, del clínico y la observación directa fueron integrados en un proceso de votación conocidos como ejercicio Delphi.

En total se escogieron 139 categorías de segundo nivel de la CIF como aquellas categorías que capturarían aspectos relevantes del funcionamiento en sujetos con un TCE y que podrían ser útiles en los encuentros multidisciplinares para constituir lo que se conoce en el mundo anglosajón como *comprehensive ICF Core sets* o conjunto mínimo integral de la CIF. Por el contrario, se escogieron 23 categorías para describir los *Brief ICF Core Sets*, como aquel conjunto mínimo breve de datos necesarios para describir el espectro funcional en ámbitos en donde fuese necesaria una descripción más concisa como puede ser en el encuentro clínico o en la realización de estudios epidemiológicos.

El objetivo de los *Core Sets*, tal y como dice la propia OMS, no es la creación de una nueva medida, pero sí una guía para poder describir en conjunto, el espectro funcional de un paciente con un TCE. Conociendo los dominios que se afectan en esta población de pacientes, se puede elaborar una guía de medidas específicas para asesorar sobre lo que se quiere medir en cada momento dado.

La sistematización en la exploración física y en la evaluación de problemas que han sido identificados por los pacientes y por los diferentes profesionales que le tratan en su conjunto se puede realizar mediante la CIF y en especial con los *ICF-TBI Core Sets*. Con ello se promociona una visión holística del conjunto de secuelas tras la lesión encefálica.

Un punto interesante en el empleo de los *Core Sets* en la clínica es que se parte de la evaluación de problemas que con anterioridad han sido citados tanto por los profesionales como por los propios pacientes, por lo que se garantiza una exploración integral de la esfera de funcionamiento. Una vez identificados los problemas del paciente, es habitual en los equipos de rehabilitación las reuniones interdisciplinares y la determinación del conjunto de intervenciones que se habrán de realizar. El hecho de emplear un lenguaje común, permite también la sistematización en la asignación de las intervenciones a los diferentes miembros del equipo. Parte de cada uno de los problemas del paciente han de ser abordados por parte de diferentes profesionales sanitarios.

Un ejemplo paradigmático sería la identificación de un problema serio en la conducta de un paciente con un TCE ingresado en una unidad de rehabilitación en fase de amnesia postraumática. Por un lado el profesional médico podrá valorar el uso de agentes farmacológicos para su control, el personal de enfermería velará porque el paciente esté en un entorno con escasez de estímulos que puedan desencadenar la agresividad y vigilarán el cumplimiento de medidas de restricción que hubiera pautado el médico. El fisioterapeuta seguramente habrá de vigilar y posiblemente tenga que minimizar temporalmente la realización de programas más ambiciosos de mejora de marcha o de función motriz. El terapeuta ocupacional intentará facilitar la orientación, la reconducción conductual y el entrenamiento en actividades muy básicas. Desde neuropsicología el abordaje irá en esa misma línea y con probabilidad en el acompañamiento y apoyo emocional a la familia.

La estratificación sistematizada de los problemas y la identificación de los diferentes miembros del equipo que participarán en las intervenciones terapéuticas para subsanarlas apunta a una mejoría en la comunicación interdisciplinar. Algunos estudios publicados en la literatura observan que el uso de la CIF puede mejorar la calidad asistencial mediante una coordinación en el trabajo y una comunicación más fluida, a la par que disminuye el tiempo empleado durante las sesiones de trabajo interdisciplinares(Tempest et al. 2012; Tempest et al. 2013; McDougall & V. Wright 2009; Tyson et al. 2012).

Este tesis con la descripción de los *ICF TBI Core Sets* deja una puerta abierta para el estudio y aplicabilidad en la práctica clínica diaria, pero también en el estudio en materia de discapacidad promoviendo una interoperabilidad semántica descriptora del funcionamiento en pacientes con TCE.

8. Conclusiones

1) No existe ningún instrumento de medida que sea capaz de capturar de forma universal el complejo espectro funcional de alguien que haya sufrido un TCE.
2) Los instrumentos de medida encontrados cubren áreas de funcionamiento de todos los dominios de la CIF, con una cierta tendencia a centrarse en aspectos del dominio de *Actividades & Participación* pero destaca la ausencia de instrumentos que evalúen la calidad de vida en personas con TCE así como una mayor profundidad en el análisis del impacto de los factores medioambientales sobre la misma.
3) La discapacidad secundaria al TCE se objetiva sobretodo en las secuelas cognitivas, emocionales y en el control de impulsos, que tienen un efecto deletéreo sobre la participación en ámbitos importantes de la vida como son las relaciones sociales y el retorno al trabajo.
4) Las restricciones y limitaciones en el dominio de las actividades y participación parecen ser los problemas que más impacto tienen sobre el funcionamiento y la discapacidad tras un TCE.
5) Contrariamente a lo encontrado en el estudio empírico, en la encuesta realizada al profesional, se encontró que había una preponderancia de respuestas vinculadas a los dominios de funciones y estructuras, lo que refleja que el paradigma médico sobre la discapacidad y el funcionamiento aún está presente en la mentalidad de los profesionales.
6) La CIF ha permitido la comparación de datos entre los diferentes profesionales y los propios pacientes demostrando su utilidad como un lenguaje neutral, eficiente e integrador y la identificación de los *ICF Core Sets* pueden servir de base para el desarrollo de nuevos instrumentos de medida y de resultado así como una mejor sistematización del encuentro clínico e interdisciplinar.

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10. Abreviaturas

APT	Amnesia postraumática
CIE	Clasificación Internacional de la Enfermedad
CIF	Clasificación Internacional del Funcionamiento, de la discapacidad y de la salud
CIQ	*Community Integration Questionnaire*
DRS	*Disability Rating Scale*
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
EPT	Epilepsia Postraumática
FIM	*Functional Independence Measurement*
GCS	*Glasgow Coma Scale*
GOAT	*Galveston Amnesia Orientation Test*
GOS	*Glasgow Outcome Scale*
OMS	Organización Mundial de la Salud
RMN	Resonancia Magnética Nuclear
TAC	Tomografía Axial Computerizada
TCE	Traumatismo Craneoencefálico
TMT	*Trail Making Test*
WAIS	*Wechsler Adult Intelligence Scale*

11. Anexo

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RESEARCH PAPER

Problems in functioning after a mild traumatic brain injury within the ICF framework: the patient perspective using focus groups

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***Purpose*: To describe problems in body functions, activities, and participation and the influence of environmental factors as experienced after mild traumatic brain injury (TBI), using the ICF framework. To compare our findings with the Brief and Comprehensive ICF Core Sets for TBI. *Methods*: Six focus-group interviews were performed with 17 participants (nine women, eight men, age ranged from 22 to 55 years) within the context of an outpatient rehabilitation programme for patients with mild TBI. The interviews were transcribed verbatim and analysed using the ICF. *Results*: One-hundred and eight second-level categories derived from the interview text, showing a large diversity of TBI-related problems in functioning. Problems in cognitive and emotional functions, energy and drive, and in carrying out daily routine and work, were frequently reported. All ICF categories reported with high-to-moderate frequencies were present in the Brief ICF Core Set and 84% in the Comprehensive ICF Core Set. The reported environmental factors mainly concerned aspects of health and social security systems, social network and attitudes towards the injured person. *Conclusions*: This study confirms the diversity of problems and the environmental factors that have an impact on post-injury functioning of patients with mild TBI.**

Keywords: functioning, ICF, patient perspective, traumatic brain injury

Implications for Rehabilitation

- Disabilities related to cognitive and emotional functions, energy and drive, and carrying out daily routine and work should be addressed in rehabilitation of people with mild traumatic brain injury (TBI).
- Attention should be given to environmental facilitators and barriers for activities and participation.
- Participation in everyday life after a mild TBI, including social- and work-participation, constitutes a challenge where multidisciplinary rehabilitation efforts should be considered.
- The Brief Core Set does not attain all frequently observed categories of functioning among people with mild TBI.

Introduction

A traumatic brain injury (TBI) is a disabling condition that affects different aspects of everyday life, including social and vocational participation [1,2]. Approximately 10 million people experience TBI every year [3]. In a study from Oslo, the Norwegian capital, the rate of patient admittance to hospitals after TBI was 83.3 per 100 000 people [4], which is similar to the rates reported from the USA [5]. People with TBI constitute a heterogeneous group with several challenges in functioning that are linked to the severity of each person's individual condition [6,7]. TBIs are usually classified as mild, moderate or severe [8]. In Europe, 70–80% of all TBIs are classified as mild based on the Glasgow Coma Scale (GCS) [9]. Despite the fact that people with mild TBI represent the largest group, they are less frequently studied than people with severe TBI [10].

Cognitive, emotional and behavioural functional problems are common to all TBI severity groups [7]. Typical impairments following mild TBI include a lack of energy and cognitive symptoms, such as reduced concentration and memory [11,12]. In a 1-year cohort of mainly mild TBI, the persistence of symptoms from the TBI, as well as activity limitations and participation restrictions, were observed during 1-year follow-up examinations [11,13].

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The experiences of people living with TBI have been studied with increasing frequency. In a recent meta-synthesis of qualitative research that included 23 studies on the experiences of recovery and outcomes after TBI, themes such as a disconnection with a person's pre-injury identity, emotional and social problems, and a feeling of loss associated with the TBI were identified [14]. However, there is a lack of comprehensive descriptions of the experiences of living with a mild TBI. In the qualitative studies that were included in the meta-synthesis [14] and in quantitative TBI studies, the focus has been on single issues, such as coping with stress [15,16], fatigue and sleep disturbances [17,18], motivation [19], learning [20,21], and executive functions [22,23]. A number of studies have addressed people's quality of life after TBI [24,25].

People living with TBI have not been regularly included in the developmental process in frequently used diagnosis-specific and generic assessments, and outcome measures that are used for TBI. A study assessing the health-related measures of quality of life (HRQOL) from a patient's perspective found that such generic instruments do not capture the full complexity of the consequences of TBI [26]. Other studies have concluded that TBI-targeted instruments that are based on comprehensive condition-specific item banks are needed to ensure the sensitive assessment of all aspects of functioning and quality of life in cases of TBI [27].

A broad picture of the impairments, activity limitations, and participation restrictions experienced by people with TBI, is necessary for appropriate rehabilitation planning and evaluation. The WHO International Classification of Functioning Disability and Health (ICF) offers an interdisciplinary framework for the comprehensive assessment and descriptions of functioning and disability in relation to a health condition [28]. According to the framework, functioning and disability are the result of interactions among five components: body functions, body structures, activities and participation, and environmental and personal factors.

The ICF classification system contains more than 1400 categories of functioning and environmental factors, which represents a challenge when they are applied to clinical practice and research. The process of developing ICF core sets has been prioritised by the WHO, making the ICF accessible for the assessment of specific health conditions. Recently, the process of developing Comprehensive and Brief ICF Core Sets for TBI was completed. This international effort includes data collections comprising a literature review, an empirical multicentre study, an expert survey, and focus-group interviews of patients that were conducted in three countries (Italy, Norway and Spain) [29]. A consensus conference and a Delphi process finalised the process [30,31]. Data from four Norwegian focus groups were submitted to the data collection process. Because the process of developing the Brief and Comprehensive ICF Core Sets for TBI builds on a multitude of approaches, including all severity levels of TBI, it is important to examine to what extent the final data sets cover the experiences of people who have sustained a mild TBI.

The present report comprises a description of analysed data from six focus groups that were conducted in Norway and included people with mild TBI. Using the ICF as a framework, the aim of the present study was to describe the problems in body functions, activities and participation as experienced by the TBI patients themselves, and to describe the environmental facilitators and barriers to everyday life, including work life. We also compared how the problems that were reported among people with mild TBI were in accordance with the categories of the Brief and Comprehensive Core Sets for TBI.

Materials and methods

Design

The WHO recommends focus groups as a means of examining experiences from the patient's perspective because this approach is especially useful for studying complex issues that entail many levels of feeling and experience [32,33]. Using a focus-group methodology, we collected qualitative data regarding functioning and disability among people with mild TBI. The interviews were performed between November 2008 and April 2010. 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]. They were also asked about the factors in their environment or living conditions that they experienced as either facilitators or barriers to functioning.

The ICF was applied both as a conceptual framework and as a tool for analysis. Conceptually, the ICF is based on an integrative model that covers functioning within its components of body functions (b), body structures (s), activities and participation (d) as well as environmental (e) and personal factors (pf). As a classification system, the ICF provides alphanumeric codes that are arranged in a hierarchical manner into chapters and more detailed categories of functioning and environmental factors. Personal factors are not included in the classification. An illustration of this categorisation within the component of Activities and participation (d) is as follows.

Chapter d2: General tasks and demands
2nd level category: d230 Carrying out daily routine
3rd level category: d2303 Managing one's own activity level.

Ethical approval for the study was obtained from the Regional Committee for Medical Research Ethics in the Eastern Health Region in Norway (approval number 171.08).

Participants

Participants between 18 and 55 years of age with diagnoses of mild TBI according to the TBI model system definition were eligible for inclusion in the study. Patients with severe cognitive dysfunction, severe pre-injury psychiatric disorders or substance abuse were excluded from the study. Injury characteristics were described using GCS scores [8], and other information about the severity of the injury from the patients' medical records. Mild TBI with GCS scores of 13–15 were categorised as uncomplicated or complicated based on whether there were positive findings on a CT or MRI with respect to the structural brain injury in the patient's medical records.

Context of the study

The study was performed within the context of an outpatient rehabilitation programme at the department of Physical Medicine and Rehabilitation at Oslo University Hospital. This programme is a multidisciplinary programme that facilitates the process of returning to work after a TBI. Patients with mild TBI who reported symptoms approximately 6 weeks after the injury received individual assessments followed by psycho-educational group interventions over four consecutive weeks. Individual follow-up sessions were offered when necessary. In the programme, a focus-group interview made up the first group session, with the intention that the group members should get to know one another and share some of the problems in functioning that they faced after their injuries.

Data collection

The groups were formed based on a convenience sample of patients who were successively included in the rehabilitation programme and in the study. The group size was set at a maximum of four to five patients after taking into account the reduced capacity found in people with TBI with respect to concentration and fatigue. Six focus-group interviews were performed. A total of 17 patients participated in the study, with two to four patients in each group. Four groups were made up of both genders, and two groups included only male or only female participants.

All focus-group sessions were conducted in a nondirective manner by two moderators, a physiotherapist (HLS) and an occupational therapist (US). Both had expertise within the fields of TBI and ICF. At the beginning of each focus group, the participants were informed about the purpose and procedure of the session. The sessions were guided by open-ended questions that were derived from the recommendations for focus groups in the development of ICF Core Sets [29,34].

1. If you think about your body and mind, what does not work the way it is supposed to?
2. If you think about your daily life, what are your problems?
3. If you think about your environment and living conditions, what do you find helpful and supportive, and what barriers do you experience?

The physiotherapist (PT) and occupational therapist (OT) moderated the discussions dealing with problems in body functions and structures, activities, participation and environmental factors. When they were not moderating, they functioned as group assistants, observing the discussions and taking notes. At the end of the session, the participants were encouraged to make use of the knowledge that was gained from the discussions in later sessions of the rehabilitation programme. The duration of the focus groups varied from 45 to 60 min. After each interview, the moderators summarised their immediate impressions from the session. The discussions were digitally recorded with an Olympus WS-331M and transcribed verbatim.

Data analysis

The transcription of the discussion for each group was first read in its entirety to obtain an overview of the collected data. The meaning condensation procedure followed the initial reading. First, the data were divided into text entities. A text entity refers to a continuous sequence of text from one discussant. The themes that dominated a text entity were determined, and the meaningful concepts within each theme were identified. All of the identified concepts were linked to the most precise category, including not-definable (nd) codes in the ICF and personal factors (pf) based on established linking rules [35]. The nd codes were nd-mental health, nd-physical health, nd-general health, nd-quality of life and nd (unspecified). The ICF codes describing problems in functioning related to comorbidities sustained in connection with the current injury were separated from the TBI-related codes.

Both moderators performed the meaning condensation and linking procedures independently for approximately half of the materials. In addition, to ensure accuracy, the two moderators and a third researcher (SØ), who was also experienced in the use of the recommended procedures [35,36], analysed the transcribed text. Thus, all text concepts were coded by two people. The identified concepts in the text entity were compared. In cases of disagreement, an agreement was established through a consultation with the third researcher until a consensus was reached. All authors are experienced in using the ICF in research and clinical practice, and two of the authors (HLS and SO) have performed similar analyses earlier [37]. We chose not to calculate the interrater reliability using kappa statistics because it does not take into consideration whether or not unequal coding refers to the same phenomenon. Partial disagreement in coding may influence the kappa values negatively. The categories d845 Acquiring, keeping and terminating a job, and d850 Remunerative employment describe the same phenomenon, but would represent a disagreement if one rater chose d845 and the other d850. Other studies have shown a moderate-to-good intertester reliability in linking the text to the ICF [37–39]. The environmental factors were analysed further with respect to whether they represented facilitators or barriers to functioning.

We retrospectively analysed the data saturation. Data saturation refers to the point at which the investigator has obtained sufficient information from the field. In this study, saturation was reached when the linking process of two consecutive focus groups each reached less than 10% of new second-level ICF categories compared with the number of second-level categories in the previous focus group [29] The saturation is shown in Figure 1.

Demographic and injury-related variables are reported as frequencies, means and standard deviations (SD), median and interquartile ranges (IQR) or ranges. The reported categories were categorised into two frequency groups: categories with high-to-moderate frequency were reported by >10% of the patients, and categories with low frequency were reported by ≤10%. For the high-to-moderate group, the results of the analysis are presented as frequencies of the second-level ICF categories in descending order, comprising references to the Comprehensive and Brief ICF Core Sets for TBI, while the low-frequency categories are presented as categories only. The nd-codes and personal factors are presented by the individual

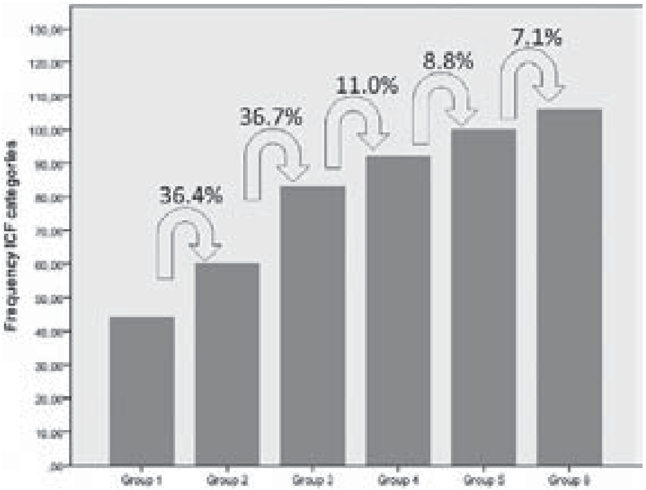

Figure 1. Saturation of second-level ICF categories, nd-codes and pf from focus groups 1 through 6. The percentage shows additional identified categories.

participant frequencies. The content of the nd codes, personal factors and comorbidities are presented separately.

Results

The mean age of the participants was 39.9 years (SD = 2.7). The participants' demographic and injury characteristics are summarised in Table I. Three out of four patients were educated at a university level, and all were employed at the time of the injury. According to the GCS score, which reflected the level of consciousness, the participants had a mild TBI; however, nine patients had structural findings on CT/MRI, reflecting more severe injuries. There were some cases of comorbidities connected with the incident, with four participants having minor fractures of the facial skeleton. Other fractures were localised to the 2nd vertebrae, the clavicula and patella. In addition, there were two cases of injury-related pain in the neck, shoulder and back. Nine out of 17 participants had no comorbidities.

A total of 881 meaningful concepts were extracted from the transcribed focus group text. In all, 108 second-level ICF categories were derived from the text analyses. Of these, nine categories were directly related to comorbidities that were sustained in connection with the TBI. The meaningful concepts that directly referred to the TBI were linked to 99 second-level ICF categories (Table II). Table II shows that there were 41 categories with high-to-moderate frequencies and 58 categories with low frequencies.

Table III shows the distribution of the high-to-moderate frequency ICF categories for body functions, body structures, activities and participation, and environmental factors. The low-frequency ICF categories are presented in Table V. The most frequently reported problems were related to cognitive functioning and the consequences of the TBI on daily functioning and living.

Table I. Characteristics of the participants and injury-related information (n = 17).

Characteristics	
Age (mean SD), range	39.9 (2.7), 22–55
Gender (n)	
Women	9
Men	8
Marital status (n)	
Married/cohabiting	9
Single	8
Education (n)	
≤12 years	4
>12 year/University level	12
Unknown	1
Employment status at the time of injury (Working or studying) (n)	17
Sick leave (n)	
Complete	8
Partial	2
None	7
GCS score (median, IQR)	14 (14–15)
Severity of TBI based on CT/MRI (n)	
Mild TBI, uncomplicated	8
Mild TBI, complicated	9
Injury mechanism (n)	
Traffic	7
Fall	7
Other	3
Weeks since injury (median, IQR)	28 (19.4–46)

Table II. High-to-moderate and low-frequency ICF second-level categories of functioning and environmental factors (comorbidities are not included).

Component	Categories of high-to-moderate frequency (n)	Categories of low-frequency (n)	Total
Body functions	13	17	30
Body structures	2	1	3
Activities and participation	14	25	39
Environmental factors	12	15	27
Total	41	58	99

Among body functions, the five most frequently reported problems were related to energy and drive functions (b130), memory functions (b144), emotional functions (b152), higher-level cognitive functions (b164), and attention functions (b140). The five most frequently reported problems in activities and participation were carrying out daily routine (d230), employment/work (d850), looking after one's health (d570), social relationships with friends (d750) and handling stress and other psychological demands (d240) (Table III).

In total, 27 environmental categories were identified. The three most frequently reported environmental factors were related to the support provided by health professionals (e355) and the corresponding health services, and social security systems (e580) and by people in positions of authority in the workplace (e330). In addition, the immediate families and their attitudes, the different products and technology used in daily life, and friends and colleagues were frequently described.

Table III. High-to-moderate frequent reported second-level ICF categories of functioning and environmental factors (n = 17) and their presence in Brief (B) and Comprehensive (C) ICF Core Sets for TBI.

ICF second-level category	Reported frequency (n)	Present in ICF TBI Core Sets
b130 Energy and drive functions	15	B, C
d230 Carrying out daily routine	13	B, C
d850 Remunerative employment	13	C
b144 Memory functions	12	B, C
b152 Emotional functions	11	B, C
d570 Looking after one's health	11	B[a], C
d750 Informal social relationships	11	C
b164 Higher-level cognitive functions	10	B, C
d240 Handling stress and other psychological demands	10	C
b140 Attention functions	9	B, C
b280 Sensation of pain	9	B, C
b134 Sleep functions	8	C
d350 Conversation	8	B, C
d920 Recreation and leisure	8	B, C
e355 Health professionals	8	C
e580 Health services, systems and policies	8	B, C
s110 Structure of brain	7	B, C
s710 Structure of head and neck region	7	C
d220 Undertaking multiple tasks	7	C
e330 People in positions of authority	7	C
b210 Seeing functions	6	C
b240 Sensations associated with hearing and vestibular function	6	C
d660 Assisting others	6	C
d760 Family relationships	6	C
e115 Products and technology for personal use in daily living	6	B, C
e310 Immediate family	6	C
e570 Social security services, systems and policies	6	B, C
b126 Temperament and personality functions	5	C
d166 Reading	5	C
d475 Driving	5	C
d720 Complex interpersonal interactions	5	B, C
e250 Sound	5	C
e325 Acquaintances, peers, colleagues, neighbours and community members	5	C
e410 Individual attitudes of family members	5	C
d450 Walking	4	B, C
e125 Products and technology for communication	4	C
e320 Friends	4	B, C
e420 Individual attitudes of friends	4	C
b110 Consciousness functions	3	C
b156 Perceptual functions	3	C
b160 Thought functions	3	C

[a]Brief ICF Core Set for TBI includes all d5 (Self-care).

The environmental categories may be coded as either facilitators or barriers to functioning. Table IV presents the 12 most frequently addressed environmental factors and whether they were regarded as facilitators or barriers. More than half of them were experienced as both facilitators and barriers.

The 58 low-frequency categories shown in Table V, point to the diversity of the problems and environmental factors that impacted post-injury functioning. These include among others several aspects of sensory functions such as vision and hearing (b2), and activities in mobility (d4) and domestic life (d6). Also many aspects of the physical environment (e1), attitudes (e4), and societal services and systems were noted (e5).

There were 38 meaningful concepts that were not assigned to a specified ICF category but were coded with not-definable (nd) codes: nd-mental health (n = 11); nd-physical health (n = 9); nd-general health (n = 3); nd-quality of life (n = 4); and nd-unspecified (n = 11). In addition, there were 23 personal factors that were described in the focus groups: age (n = 3); marital status (n = 2); education and profession (n = 7); and personality factors (n = 11). The personality factors were descriptions, such as "I am an energetic fellow"; "I require a lot of myself"; "I'm a sociable guy"; "I'm a conscientious person"; and "I'm lazy and pragmatic".

Problems in functioning and environmental factors that were related to comorbidities were reported by four people. Table VI shows that the problems included bodily injuries, such as injuries of the upper and lower extremities and trunk, limitations in activities and also technical aids related to these impairments.

Discussion

The aim of this study was to describe the personal experiences and functional problems after sustaining a mild TBI.

Table IV. The environmental factors (e-categories) that were most frequently addressed, and categorised as facilitators and/or barriers to functioning (n = 17).

E-categories		Facilitator	Barrier
e115	Products and technology for personal use in daily living	×	×
e125	Products and technology for communication	×	×
e250	Sound	n.i.	×
e310	Immediate family	×	×
e320	Friends	×	n.i.
e325	Acquaintances, peers, colleagues, neighbours and community members	×	×
e330	People in positions of authority	×	n.i.
e355	Health professionals	×	×
e410	Individual attitudes of friends	×	×
e420	Individual attitudes of friends	n.i.	×
e570	Social security services, systems and policies	×	n.i.
e580	Health services, systems and policies	×	×

n.i., not identified.

Table V. Low-frequency second-level ICF categories presented according to ICF chapters.

ICF Chapter	ICF Category
b1 Mental functions	b147 Psychomotor functions, b167 Mental functions of language, b172 Calculation functions
b2 Sensory functions and pain	b220 Sensations associated with the eye and adjoining structures, b230 Hearing functions, b235 Vestibular functions, b255 Smell functions, b260 Proprioceptive function, b270 Sensory functions related to temperature and other stimuli
b3 Voice and speech functions	b320 Articulation functions, b340 Alternative vocalisation functions
b4 Functions of the cardiovascular, haematological, immunological and respiratory systems	b410 Heart functions, b420 Blood pressure functions, b440 Respiration functions, b455 Exercise tolerance functions
b5 Functions of the digestive, metabolic and endocrine systems	b510 Ingestion functions, b535 Sensations associated with the digestive system
s4 Structures of the cardiovascular, haematological, immunological and respiratory systems	s410 Structure of cardiovascular system
d1 Learning and applying knowledge	d110 Watching, d160 Focusing attention, d170 Writing, d175 Solving problems
d2 General tasks and demands	d210 Undertaking a single task
d3 Communication	d330 Speaking, d345 Writing messages, d360 Using communication devices and techniques
d4 Mobility	d410 Changing basic body position, d415 Maintaining a body position, d430 Lifting and carrying objects, d455 Moving around, d460 Moving around in different locations
d5 Self-care	d510 Washing oneself, d540 Dressing
d6 Domestic life	d620 Acquisition of goods and services, d630 Preparing meals, d640 Doing housework, d650 Caring for household objects
d7 Interpersonal interactions and relationships	d710 Basic interpersonal interactions, d740 Formal relationships, d770 Intimate relationships
d8 Major life areas	d830 Higher education, d845 Acquiring, keeping and terminating a job
d9 Community, social and civic life	d910 Community life
e1 Products and technology	e110 Products or substances for personal consumption, e135 Products and technology for employment, e140 Products and technology for culture, recreation and sports, e155 Design, construction and building products and technology of buildings for private use
e2 Natural environment and human-made changes to environment	e225 Climate, e240 Light
e3 Support and relationships	e315 Extended family
e4 Attitudes	e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members, e430 Individual attitudes of people in positions of authority, e450 Individual attitudes of health professionals, e460 Societal attitudes
e5 Services, systems and policies	e535 Communication services, systems and policies, e565 Economic services, systems and policies, e585 Education and training services, systems and policies, e590 Labour and employment services, systems and policies

Table VI. Second-level ICF categories of problems in functioning and environmental factors related to the comorbidities sustained in connection with mild TBI presented according to the ICF components.

ICF Component	ICF Categories
Body functions	b280 Sensation of pain (extremity fracture), b715 Stability of joint function
Body structures	s320 Structure of mouth, s720 Structure of shoulder region, s730 Structure of upper extremity, s750 Structure of lower extremity, s760 Structure of trunk
Activities and participation	d415 Maintaining a body position, d445 Hand and arm use, d450 Walking, d465 Moving around using equipment
Environmental factors	e120 Products and technology for indoor and outdoor mobility and transportation, e580 Health services, systems and policies

The methodological approach included focus-group interviews within the context of an ICF framework. By dividing the coded material into high-to-medium frequency and low-frequency reported categories, we were able to highlight the typical problems that are faced by patients after a mild TBI. Problems reported with high-to-moderate frequencies were related to cognitive and emotional functions, energy and drive, and to carrying out daily routine and work, and associated environmental factors. At the same time, the patients provided diverse descriptions, as shown by the numerous factors that were reported with low frequency.

Regarding body functions, problems in mental functions related to energy and drive (fatigue), attention, memory and executive function, and the emotional impact of a TBI were reported by more than half of the patients in our study. The participants also reported perceptual problems and reduced abilities in retaining thoughts or thinking through problems as an expression of memory and higher cognitive functions. These findings are in accordance with other studies of post-injury functioning after a TBI [40,41]. In the clinical study by Laxe et al. that comprised people with more severe TBI than in the current study, parallel impairments in cognition and mental health were reported by more than 75% of the patients [40]. In a meta-analysis, moderate-to-large effect sizes on post-concussion syndrome were reported for executive functions, memory, attention and visual-spatial skills [42]. In Levack et al.'s metasynthesis of qualitative research, there were descriptions of a loss of bodily abilities in a mind/body disconnect that included being slower in cognitive activities, being emotionally labile, and lacking stamina [14].

Fatigue appears to be a common problem independent of injury severity, and was reported as a major problem in our findings as well. Almost one-third of a cohort of patients with mild TBI reported severe levels of fatigue in a study comprising patients with and without CT/MRI findings [41]. In that study, headaches and nausea on admission were associated with fatigue 6 months post-injury. Headaches and also sleep disturbances were reported by more than half of the participant in our study, which was in accordance with the study of Sigurdardottir et al. where 40% of patients with mild TBI reported sleep disturbances and 45% suffered from headaches 3 months post-injury [43]. In another study with follow-up at 3 months post-injury, patients with mild TBI reported more headaches, fatigue and problems in concentration than in a trauma control group without TBI [44]. Furthermore, they also experienced sleep problems, sensitivity to noise, and visual disturbances. Problems in vision and sound sensitivity were reported by approximately one-third of the participants in our study. Problems with concentration and fatigue [41] as well as sensitivity to sound as reported in our study were highly related to restricted interaction with friends.

Pertaining to the patients' activities and participation, problems in carrying out daily routines and handling stress and psychological demands represented problems that were reported at high frequencies. A likely explanation of these findings is that the patients might expend energy and effort on resuming former activities and activity levels too soon after their injuries. Koskinen et al. [45] performed an ICF linking process to compare the QOLIBRI, a HRQOL instrument for TBI, with a functional assessment on the Glasgow Outcome Scale – Extended (GOSE). They also performed assessments according to an extended ICF checklist based on information from the patients' medical records [27,45]. Functions, such as carrying out daily routine and handling stress and psychological demands, which were frequently reported in our study, were not addressed by any of the assessed instruments. In a study of patient records from a rehabilitation institution, problems in undertaking multiple tasks and carrying out daily routine were reported for approximately 25% of the patients [46].

Other problems that are essential for daily living and participation were also reported by the participants in our study. These include activities such as performing of multiple tasks, social interactions, parenting and participation in leisure activities, which were strained after the injury. The patients' work and sick leave status supports the fact that more than 75% of the patients reported problems with participation in work. Most of the above mentioned problems were also reported in the study by Laxe et al. [40].

The recovery process, taking care of one's health and the provision of healthcare services are main concerns after a TBI. Two out of three participants reported that regaining their health, coded as "looking after one's health" in the ICF was an important issue. Regaining one's health was also recognised as a main concern of rehabilitation in Laxe et al.'s study [40]. The effort of regaining functioning combined with a reduced capacity postinjury, may explain the high rates of problems with daily activities, routines and stressful situations. A literature review shows that frustration with unrecognised mild TBI-related disabilities and a lack of treatment could adversely influence social functioning [47]. Thus, one would expect the interaction of health professionals to be important; however, in our study their support was perceived as both facilitators and barriers. In the Spanish study, more than 80% of patients found health services to be facilitators [40].

Apart from the health and social security systems, significant environmental factors in our study were particularly related to people who constitute the environment of the patients, including immediate family, friends and workplace colleagues. The study of Laxe et al. showed family relationships to be very important and a facilitator for functioning in more than 90% of the patients [40]. We also recognised that the presence of colleagues, friends and acquaintances were predominantly reported as facilitators. Individual attitudes of friends, however, were sometimes experienced as barriers, expressed as "my friends don't understand my situation". The TBI metasynthesis by Levack et al. described a feeling of social disconnection by people with TBI that was attributed to stigmatisation by other people and other people raising questions about the validity of their disabilities when they looked "normal" [14]. Perceived social support was associated with community integration and life satisfaction in a study of patients 3 years after a mild TBI [48].

The 58 categories that convey problems and environmental factors that were reported with low frequencies also provide essential knowledge about the consequences of mild TBI. They point to the diversity of problems and the need for individually tailored rehabilitation processes.

There are also some clusters of phenomena that could be described across the high-to-moderate-frequency and low-frequency groupings. One group involves the mental and cognitive problems that were thoroughly described by the participants. A second group concerns the sensory functions and their assumed consequences for watching, reading and writing. A third pertains to the breadth of reported consequences of TBI in the organisation and solving of tasks and demands of everyday life. A fourth cluster refers to social functioning and social networks, including work relationships.

Most categories in the current study (84%) are also present in the Comprehensive ICF Core Set [31]. All the categories in the high-to-moderate frequency group, and 42 of the categories (72%) reported in the low frequency group are present in the Comprehensive ICF Core Set. In contrast, there are only two categories in the Brief ICF Core Set that were not represented in the present study [31]. They were b760, Control of voluntary movement functions, and d845, Acquiring and keeping and terminating a job. The first category may be more valid for people with severe TBI than for patients with mild injuries. The fact that at the study start all participants were working or on sick leave from their current occupation, can explain the use of the ICF d850 Remunerative employment instead of the category d845 that focus more on getting and keeping a job.

The current study also sheds light on the validity of the Brief ICF Core Set for TBI as a tool for the assessment of functioning after a mild TBI [31]. More than half of the categories that reflected problems reported with a high-to-moderate frequency are not included in the Brief ICF Core Set. Problems in sleep, handling stress and psychological demands, maintaining friendships (informal relationships) and managing work duties were reported by more than half of the participants, but these categories are not present in the Brief ICF Core Set [31]. Moreover, the requirements of carrying out daily routine were reported by more than half of the participants. This finding indicates that the burden of trying to function with the requirements of everyday life is a challenge after a mild TBI. Achieving a return to work or remaining in the person's current position may constitute a challenge in which multidisciplinary rehabilitation efforts will be required.

Structure of the brain is an ICF category that reflects problems that are mostly described in an individual's diagnosis but might not be visible as a structural injury on a CT/MRI for people with mild TBI. In our study, eight participants had a diagnosis of commotio cerebri without complications, whereas the nine other participants had structural injuries of the brain that were recognised on CT/MRI examinations. Having a mild TBI diagnosis was a precondition for participating in the rehabilitation programme and was not routinely specified further by more than half of the participants.

The strength of this study is that the results were derived from almost 900 meaningful concepts, and that we reached satisfactory data saturation. The study also had some limitations. The participants were in the age group 22–55 years, thus the results mainly apply to a population of working age. Moreover, the results are limited to adults who were employed at the time of injury because this current study was part of a return-to-work project. The study population belongs to the group mild TBI, however, based on the CT/MRI findings, the results apply to persons with more complicated mild TBIs.

In conclusion, the participants described diverse consequences of the TBI and associated environmental factors that influence their post-injury functioning. The frequently addressed problems are all present in the Comprehensive ICF Core Set for TBI, whereas some frequently reported problems are not included in the Brief ICF Core Set for TBI.

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