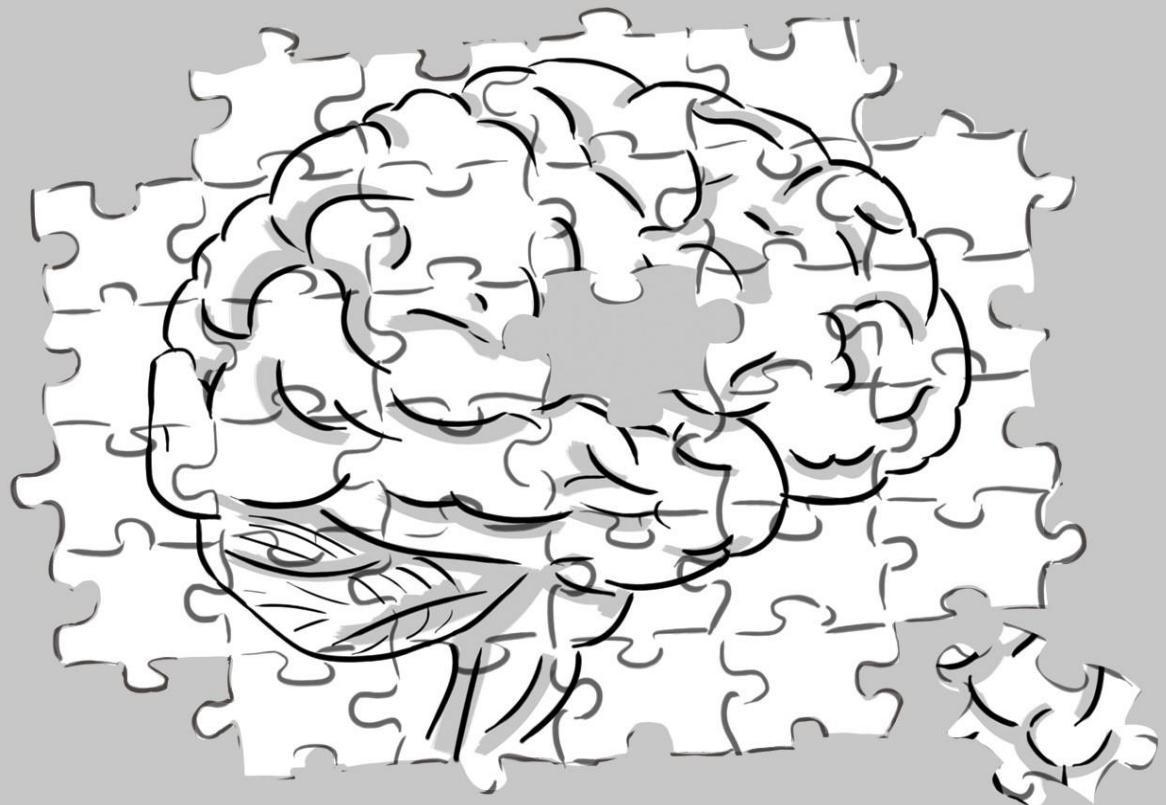


# **Self-awareness in patients with acquired brain injury: clinical intervention and its impact on patient's functional independence**

**PhD Thesis**



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**TESIS DOCTORAL**

**Self-awareness in patients with acquired brain  
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patient's functional independence**

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*A mi familia,*



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## **Glossary of abbreviation**

ABI	Acquired brain injury
AD	Awareness of deficit
ADD	Assessment of awareness of disability
AMPS	Assessment of Motor and Process Skills
AQ	Awareness Questionnaire
BI-m	Barthel Index-modified
CEADAC	Centro de referencia estatal de atención al daño cerebral
DCA	Daño cerebral adquirido
DCMA	Dynamic Comprehensive Model of Awareness
DRS	Disability Rating Scale
ECD	Escala de Conciencia de Déficit
FEDACE	Federación Española de Daño Cerebral
FPCN	Fronto-parietal control network
fMRI	Functional magnetic resonance imaging
FIM	Functional Independence Measure
GCS	Glasgow Coma Scale
HIBS	Head-Injury -Behaviour Scale
ILS	Independent Living Scale
Lawton IADL	Lawton Instrumental Activities of Daily Living Scale

MPAI	Mayo-Portland Adaptability Inventory
OMS	Organización Mundial de la Salud
PCRS	Patient Competency Rating Scale
PFC	Prefrontal cortex
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOLIBRI	The Quality of Life in Brain Injury
SA	Self-awareness
SADI	Self-Awareness of Deficit Interview
SPIRQ	Self-perceptions in Rehabilitation Questionnaire
SIP	Sickness Impact Profile
SRSI	Self-Regulation Skills Interview
TTT	The Tinkertoy Test
VIS	Vocational Independence Scale
WHO	World Health Organization

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### **1. Introducción general**

Sufrir un daño cerebral adquirido (DCA) tiene consecuencias drásticas para el paciente y su entorno. Las secuelas más habituales de un DCA afectan sobre todo a nivel motor, conductual, cognitivo y emocional, y provocan importantes repercusiones en la vida diaria del paciente.

Un síntoma habitual de estos pacientes es que no sean conscientes de los déficits que la lesión les ha causado y especialmente de la discapacidad que les genera, presentando lo que se conoce como una afectación de la conciencia de déficit (también conocida como anosognosia) (Ownsworth et al., 2007). La afectación de la conciencia de déficit no es una característica exclusiva de los pacientes con DCA, ésta también está presente, y tiene efectos relevantes, en otras patologías como las enfermedades neurodegenerativas (Gainotti, 2018), enfermedades psiquiátricas (Poletti et al., 2012), o trastornos por abusos de sustancias (Le Berre & Sullivan, 2016).

Los pacientes con baja conciencia de déficit muestran poca motivación hacia el proceso rehabilitador, se plantean objetivos poco realistas, y pueden realizar acciones que supongan un riesgo para ellos mismos y para los demás (Malec & Moessner, 2000; Smeets, Vink, Ponds, Winkens, & van Heugten, 2015). Así mismo, una baja conciencia de déficit se asocia a peores resultados en el proceso rehabilitador y a un menor grado de independencia funcional (Ekstam, Uppgard, Kottorp, & Tham, 2007; Ownsworth & Clare, 2006).

Explorar los correlatos cerebrales asociados a una conciencia de déficit afectada ha generado interés en numerosos investigadores. Este fenómeno

se ha asociado tradicionalmente a lesiones en el hemisferio derecho del cerebro y, en particular, a áreas que comprenden regiones anteriores. Sin embargo, en las últimas décadas, y debido a la popularización el empleo de técnicas de neuroimagen que permiten analizar el funcionamiento cerebral en términos de conexiones cerebrales, la evidencia sugiere que la afectación de la conciencia de déficit está asociada a desconexiones entre regiones relevantes integradas en diferentes redes cerebrales. Éstas podrían incluir la corteza prefrontal dorsal (Schmitz, Rowley, Kawahara, & Johnson, 2006) y la fronto-parietal (Ham et al., 2014), si bien estos estudios son aún poco concluyentes. Además, las últimas teorías y modelos de la conciencia de déficit, que consideran no sólo el componente neuropsicológico asociado a la misma, sino también la importancia de aspectos puramente psicológicos y emocionales, sugieren que el fenómeno completo probablemente requiera de redes más distribuidas que integren a su vez regiones subcorticales y del tronco encéfalo (Philippi et al., 2012).

El interés por el estudio de la conciencia de déficit como un factor importante en el estado cognitivo de los pacientes con DCA ha crecido en las últimas décadas, dando lugar a diferentes teorías o modelos explicativos a nivel teórico. El primero de ellos, conocido como *Modelo de la Pirámide* (Crosson et al., 1989), divide la conciencia de déficit en tres niveles jerárquicos: en la base se encuentra la conciencia intelectual (la habilidad del paciente para reconocer sus déficits o funciones afectadas), en segundo lugar la conciencia emergente (la habilidad de percibir y describir las dificultades que el paciente presenta en el momento en que están ocurriendo), y en tercer lugar la conciencia anticipatoria, que hace referencia a la capacidad de predecir las dificultades que la persona se puede encontrar cuando se enfrenta a una tarea determinada (Crosson et al., 1989).

Un segundo modelo, el *Modelo Dinámico Integral de la Conciencia* (Toglia & Kirk, 2000), remarca exclusivamente la interacción entre dos componentes fundamentales de la conciencia de déficit: el metacognitivo, que hace referencia al conocimiento general sobre las propias habilidades; y el online, en relación con la conciencia sobre el rendimiento *in situ* durante la realización de una tarea o actividad. Por último, el *Modelo Biopsicosocial de la Conciencia* (Ownsworth, Clare, et al., 2006), contempla diferentes factores asociados a la conciencia de déficit: neuropsicológicos, psicológicos y sociales. Los primeros están relacionados con el daño en sí mismo, que a nivel neuropsicológico causan la afectación de la conciencia de los déficits y las dificultades en el día a día. Los factores psicológicos incluyen aspectos emocionales relacionados con la enfermedad, la presencia de negación, así como el estilo de afrontamiento. Por último los factores sociales incluyen interacciones con otras personas (familiares, amigos y profesionales) y también otros aspectos culturales como el estigma asociado a la enfermedad.

Todos los modelos presentados han aportado información relevante para el avance del conocimiento sobre la conciencia de déficit en pacientes con DCA. En la actualidad, se considera fundamental conocer las diferencias entre el componente metacognitivo y online a la hora de diseñar y elegir escalas de evaluación de la conciencia de déficit, e igualmente cuando el objetivo es intervenir sobre ella. Así mismo, distinguir los aspectos neuropsicológicos y emocionales/psicológicos vinculados a una conciencia de déficit afectada, resulta imprescindible para abordar de forma precisa este aspecto tan relevante en el proceso rehabilitador.

No obstante, la conciencia de déficit no es un proceso aislado en sí mismo, e independiente del resto del funcionamiento cognitivo. El abordaje de la conciencia de déficit requiere considerar su componente

metacognitivo. La metacognición puede entenderse como una función cognitiva de orden superior relacionada con el conocimiento y las creencias sobre las habilidades cognitivas de uno mismo; se trata de una capacidad crucial para comprender y optimizar la forma en que aprendemos, recordamos y actuamos, lo que nos permite evitar estrategias que no han sido eficaces en el pasado y seguir usando aquellas que sí lo han sido (O'Leary & Sloutsky, 2019). Teniendo en cuenta esta consideración de la conciencia de déficit, resulta fundamental conocer cómo ésta se relaciona con otros procesos cognitivos de orden superior, fundamentalmente la memoria y las funciones ejecutivas. Por una parte, algunos estudios han hallado relaciones directas entre la conciencia de déficit y medidas de memoria (Long, Rager, & Adams, 2014); otros estudios, sin embargo, han profundizado en la relación entre función ejecutiva y conciencia de déficit, mostrando relaciones tanto a nivel general (Hart, Whyte, Kim, & Vaccaro, 2005), como en procesos específicos de flexibilidad cognitiva (Bivona et al., 2008; Ciurli et al., 2010) e inhibición (Bogod, Mateer, & MacDonald, 2003).

A partir de las descripciones iniciales de estas relaciones, estudios posteriores han empleado análisis de regresión para caracterizar el valor predictor de algunas funciones cognitivas en la conciencia de déficit. En primer lugar, se ha sugerido que el rendimiento en memoria podría predecir el nivel de conciencia de déficit en pacientes con DCA (Noé et al., 2005; Zimmermann, Mograbi, Hermes-Pereira, Fonseca, & Prigatano, 2017). Además, el rendimiento en función ejecutiva, particularmente en procesos de monitorización y flexibilidad cognitiva (Morton & Barker, 2010; Noé et al., 2005; Zimmermann et al., 2017), inhibición (Bogod et al., 2003) y categorización (Goverover, 2004) parece ser también un buen predictor del nivel de conciencia de déficit.

El primer paso en el abordaje de cualquier proceso cognitivo, requiere poder realizar una adecuada evaluación del mismo. Se han diseñado numerosos instrumentos y escalas con la finalidad de medir de forma precisa la conciencia de déficit, las cuales se pueden clasificar en tres grupos en función de la perspectiva que emplean para realizar la evaluación:

1. Comparar la autoevaluación del paciente en un cuestionario sobre sus habilidades funcionales, con la calificación a una versión homóloga del mismo cuestionario completado por un familiar o allegado cercano. La escala más utilizada dentro de este tipo de sistema de evaluación es la Patient Competency Rating Scale (PCRS) (Prigatano et al., 1986), aunque existen otras destacables como el Awareness Questionnaire (AQ) (Sherer, Bergloff, Boake, High, & Levin, 1998).
2. A través de una entrevista semiestructurada que el clínico hace al paciente profundizando en la percepción sobre su estado, sus habilidades, las dificultades que percibe, o los objetivos que se plantea. Posteriormente, utilizando su juicio clínico (el terapeuta debe conocer de forma precisa el estado del paciente), califica si su conciencia se ajusta a la realidad. La escala más empleada es la Self-Awareness of Deficits Interview (SADI) (Fleming, Strong, & Ashton, 1996).
3. Comparar la autoevaluación del paciente con su rendimiento en tareas concretas *in vivo*, como el desempeño en pruebas neuropsicológicas. En este tipo de evaluaciones el paciente hace una previsión de su ejecución en una determinada tarea y posteriormente se compara con el rendimiento real en la misma (tiempo, número de aciertos y de errores, etc).

La consideración del aspecto metacognitivo de la conciencia de déficit, o del componente online, resulta fundamental a la hora de seleccionar un instrumento de medida u otro. Mientras que las escalas correspondientes a los dos primeros grupos mencionados, evalúan el conocimiento y las creencias del paciente sobre su estado, dificultades y rendimiento general (conciencia intelectual del modelo de Crosson et al., 1989), el tercero de ellos está basado en el aspecto online (conciencia emergente y anticipatoria) (Brown et al., 2019).

En el presente trabajo hemos abordado fundamentalmente el componente metacognitivo de la conciencia de déficit. Los dos métodos mencionados que la evalúan desde esta perspectiva presentan ventajas y limitaciones. La literatura ha señalado que comparar la autoevaluación del paciente con la de un allegado puede resultar en ocasiones inadecuado ya que, especialmente cuando el daño cerebral es reciente, la persona cercana al paciente puede tener una opinión también poco ajustada a la realidad, debido a su estado emocional afectado y a la dificultad de aceptar lo ocurrido (Fleming et al., 1996; Prigatano, Borgaro, Baker, & Wethe, 2005). Sin embargo, el conocimiento que tiene el clínico sobre el paciente suele ser más limitado que el de una persona cercana al mismo, especialmente en el grado de conocimiento sobre el paciente antes de la lesión, y en el desempeño actual en contextos reales, fuera del ambiente de la rehabilitación. Por este motivo, si el clínico es quién juzga el grado de conciencia de déficit del paciente, éste debe ser un profesional de referencia, que forme parte de su proceso rehabilitador y tenga un conocimiento amplio sobre su estado y evolución.

En los estudios que contiene el presente trabajo, para evaluar la conciencia de déficit se ha empleado una escala diseñada *ad-hoc* en el Centro de Referencia Estatal de Atención al Daño Cerebral (CEADAC). Se

trata de una entrevista semiestructurada en la que el clínico profundiza sobre el grado de conciencia del paciente en tres dimensiones: lesión, déficit y discapacidad. En la dimensión de conciencia de la lesión, el clínico asigna una puntuación (de 0 a 6) dependiendo de si el paciente reconoce haber sufrido una lesión cerebral o no, ya sea espontáneamente o en respuesta a preguntas más específicas. En la dimensión de conciencia de déficit, la puntuación (de 0 a 12) depende de si el paciente refiere espontáneamente presentar déficits físicos, sensoriales, cognitivos o emocionales, si necesita ayuda o ejemplos para reconocerlos o, si por el contrario, los ignora. Finalmente, la dimensión de conciencia de la discapacidad (puntuación de 0 a 12), se completa preguntando al paciente si cree que es capaz o no de realizar una serie de actividades (conducir, preparar una comida, trabajar o estudiar, etc.). Por tanto, la puntuación máxima en la escala es de 30, que indica un adecuado nivel de conciencia de déficit.

Si bien el modelo de medida y el formato son similares a los de la SADI, esta escala fue expresamente diseñada, y se ha usado en los estudios, porque se ajusta mejor al perfil de pacientes del centro (con el daño cerebral reciente), al incluir el apartado de conciencia de la lesión, el cuál es más habitual que esté alterado en estas fases iniciales. Además, tiene un rango de puntuación mayor que permite un resultado final más específico.

En los pacientes con DCA, presentar un bajo nivel de conciencia de déficit influye en su proceso rehabilitador y en los beneficios del mismo, por lo que su abordaje específico se ha convertido en un elemento prioritario en los programas de intervención. Son numerosas las técnicas que se han empleado para mejorar la conciencia de déficit, entre las que destacan la psicoeducación, diferentes tipos de feedback, comparar la autoevaluación del paciente con el desempeño real en la tarea, la terapia conductual y la psicoterapia (Lucas & Fleming, 2005). A lo largo de la literatura, se han

diseñado e implementado diferentes programas que, a través del empleo de algunas de estas técnicas, han mostrado ser eficaces para aumentar la conciencia de déficit de los pacientes con DCA (Leung & Liu, 2011; Schrijnemaekers, Smeets, Ponds, van Heugten, & Rasquin, 2014). La técnica más empleada es el feedback (Schmidt, Lannin, Fleming, & Ownsworth, 2011), que puede ser suministrado de forma verbal por parte del terapeuta, y que describe los aspectos positivos y negativos del rendimiento del paciente en una tarea. Puede igualmente administrarse en formato de intervención grupal, en el que el resto de pacientes implicados también colaboran en la provisión de feedback. Por otro lado, algunos estudios han empleado grabaciones de video sobre la ejecución del propio paciente.

La selección de qué técnicas incluir en el programa de intervención para abordar la conciencia de déficit de un paciente con DCA, debe realizarse según Fleming & Ownsworth, (2006) considerando los factores (neuropsicológicos, psicológicos y sociales) (Ownsworth, Clare, et al., 2006) más relevantes en el perfil de cada paciente. Por ejemplo, el uso del feedback y la realización de tareas en vivo y estructuradas, resultaría particularmente efectiva en aquellos pacientes con problemas ejecutivos que estén influyendo en la falta de conciencia de déficit. Por el contrario, aquéllos que niegan sus déficits, debido a mecanismos psicológicos y emocionales subyacentes, podrían beneficiarse en mayor medida de una aproximación basada en una buena alianza terapéutica y en el uso de la psicoeducación, la psicoterapia y la promoción y reforzamiento de la aceptación del cambio.

En la mayor parte de los casos, las investigaciones que implementan un programa específico de intervención sobre conciencia de déficit, evalúan el éxito del mismo en términos del aumento logrado sobre ésta. Sin embargo, el objetivo final de cualquier programa de rehabilitación debe ser

conseguir la mayor independencia funcional del paciente, es decir, la mayor autonomía en las actividades del día a día. Dicha relación entre la conciencia de déficit y la independencia funcional ha sido estudiada, hallándose que aquellos pacientes con una adecuada conciencia de déficit, logran mejores resultados tras la rehabilitación (Ownsworth & Clare, 2006), siendo más independientes para las actividades instrumentales de la vida diaria (Giles et al., 2019).

Así mismo, en una reciente revisión, Engel, Chui, Goverover, & Dawson, (2017) concluyeron que los pacientes que realizan un programa específico de intervención en conciencia de déficit, mejoran en actividades no entrenadas aunque parecidas a las presentes en la intervención (transferencia cercana), así como en otras diferentes, más relacionadas con las actividades del día a día. Estos resultados sugieren que los beneficios inducidos por la intervención específica sobre la conciencia de déficit pueden transferirse parcialmente a actividades de la vida diaria, estableciendo de esta manera relación entre la mejora en conciencia y el grado de independencia funcional de los pacientes con DCA.

## **2. Objetivos**

El objetivo principal de este trabajo es abordar la conciencia de déficit en pacientes con DCA, profundizando en la necesidad de realizar un abordaje específico de ésta dentro del proceso global de rehabilitación. Para ello, la investigación desarrollada se presenta estructurada en tres grandes apartados correspondientes a tres estudios ya publicados, los cuales presentan objetivos e hipótesis específicos.

El primero de ellos tenía como objetivo principal realizar una revisión sistemática de la literatura centrada en el papel de la conciencia de déficit en

la rehabilitación del DCA. Tras una primera conceptualización de la conciencia de déficit, los objetivos específicos de la revisión sistemática se centraron en evaluar el estado de la literatura en tres aspectos relevantes: la relación entre la conciencia de déficit y funcionamiento cognitivo, las técnicas y los programas de intervención específicos para abordar la conciencia de déficit y la eficacia lograda, y por último, la relación entre la mejora en conciencia de déficit y la independencia funcional en las actividades de la vida diaria.

El segundo estudio incluido corresponde a un trabajo clínico y experimental en el cual se diseñó, implementó y evaluó la eficacia de un programa de intervención específico sobre conciencia de déficit en pacientes con DCA. El programa contiene herramientas y técnicas que han mostrado ser eficaces para mejorar la conciencia de déficit de estos pacientes. Dicho programa fue implementado en el CEADAC a diferentes grupos de pacientes, y se evaluó su eficacia mediante la comparación de estos con un grupo control equivalente. Así mismo, el trabajo tenía como objetivo explicar de forma pormenorizada y detallada en qué consiste el taller, qué técnicas de abordaje de la conciencia se usan, cómo se organizan y distribuyen las sesiones, los materiales empleados, etc. En definitiva toda la información necesaria para que pueda ser utilizado por otros profesionales que encuentren útil y adecuado su uso.

El tercer estudio tenía como objetivo explorar la relación potencial entre la conciencia de déficit y el nivel de independencia funcional de los pacientes con DCA, ya que el objetivo principal de cualquier programa de rehabilitación, debe ser lograr que los pacientes sean lo más independientes posibles en su día a día. Para ello se exploró la relación entre la mejora en conciencia de déficit alcanzada por los pacientes, con la mejora funcional en las actividades instrumentales de la vida diaria.

### **3. Resultados**

#### **3.1. Primer estudio**

Los resultados obtenidos a raíz del trabajo de revisión mostraron que la conciencia de déficit considerada como un proceso metacognitivo, está ligada a otros procesos cognitivos de orden superior como las funciones ejecutivas (Bogod et al., 2003; Ciurli et al., 2010; Goverover, 2004; Hart et al., 2005; Morton & Barker, 2010) y la memoria (Long et al., 2014; Noé et al., 2005; Zimmermann et al., 2017).

Así mismo, se ha podido comprobar que en las últimas décadas se han llevado a cabo diferentes trabajos que han diseñado e implementado programas de intervención específicos sobre conciencia de déficit y que han demostrado su eficacia (Fleming & Ownsworth, 2006; Leung & Liu, 2011; Lucas & Fleming, 2005; Schrijnemaekers et al., 2014). Las técnicas empleadas varían de una aproximación a otra, siendo las más habituales la psicoeducación, diferentes tipos de feedback, la comparación de la autoevaluación con el desempeño real en la tarea, la terapia conductual y la psicoterapia.

Ante la necesidad de evaluar el éxito de la intervención sobre la conciencia de déficit en términos de mejora funcional, hasta la fecha, de los once estudios que han explorado esta relación, siete de ellos encontraron correlaciones significativas entre la mejora en conciencia de déficit lograda con el programa de intervención administrado, y unos mejores resultados funcionales en las actividades de la vida diaria (Goverover, Johnston, Toglia, & Deluca, 2007; Malec & Moessner, 2000; Ownsworth & McFarland, 2004; Ownsworth, McFarland, & Young, 2000; Skidmore, Swafford, Juengst, & Terhorst, 2018; Tham, Ginsburg, Fisher, & Tegnér, 2001; Villalobos, Bilbao, López-Muñoz, & Pacios, 2019).

### **3.2. Segundo estudio**

En el segundo estudio, se presenta un programa de intervención específico creado para aumentar la conciencia de déficit en pacientes con DCA, dentro de un programa de rehabilitación integral. Los resultados mostraron que los pacientes que recibieron el programa específico de intervención sobre la conciencia de déficit, obtenían una mejora significativa de la conciencia en comparación con los pacientes del grupo control. Dicha mejora se observó en todas las dimensiones de la conciencia exploradas: lesión, déficit y discapacidad.

Por último, se comprobó que los pacientes con un nivel inicial menor de conciencia de déficit previo al tratamiento, fueron aquellos que mostraron un mayor grado de mejoría después de recibir el programa de intervención.

### **3.3. Tercer estudio**

En primer lugar los resultados mostraron que existía una diferencia significativa en el grado de independencia funcional entre ambos grupos, de modo que los pacientes que recibieron el programa de intervención mostraron resultados funcionales más altos en la evaluación realizada después de la intervención. Para confirmar que los cambios en conciencia logrados con el programa específico de intervención estaban relacionados con dicha mejora funcional, se exploró la relación entre el grado de mejora de la conciencia de déficit y el grado de mejora funcional. Los resultados mostraron una correlación tendente a la significatividad, sugiriendo una relación potencial que apuntaba que los pacientes con un grado de mejora mayor de la conciencia de déficit (después del programa de intervención), exhibían posiblemente una mayor mejora funcional después del proceso de rehabilitación.

A continuación se comprobó si el nivel de conciencia que tenían los pacientes antes de realizar el programa de intervención, podía influir en la relación entre la mejora de ésta y la mejora funcional. Para ello se exploró la relación entre la mejora de la conciencia y la mejora funcional, controlando el efecto de las puntuaciones de conciencia previas al tratamiento. Los resultados de este análisis mostraron una correlación positiva significativa, de tal manera que es posible que los pacientes con muy poca conciencia inicial, aunque pueden experimentar grandes mejoras después del programa de intervención, no lleguen al nivel suficiente para experimentar una mejora sustancial en el resultado funcional.

Por último, se estudió dicha relación en la muestra total de pacientes y se observó que el aumento de la conciencia de déficit (inducido o no por el programa específico de intervención), se relaciona con el aumento en el grado de independencia funcional.

#### **4. Discusión general**

El DCA es una realidad que afecta de forma relevante a nuestra sociedad. Según datos de la Organización Mundial de la Salud (OMS), esta enfermedad representa la tercera causa de muerte y la primera de discapacidad en los adultos. Constituye uno de los problemas de salud más importantes en los países del “primer mundo” por el número de muertes que ocasiona y por las consecuencias derivadas, en términos de secuelas y discapacidad. En concreto en España, según FEDACE (Federación Española de Daño Cerebral), viven 420.000 personas con DCA, y cada año se dan más de 100.000 casos nuevos (Quedaza, Huete, & Bascones, 2013).

Considerando este hecho, el desarrollo del conocimiento dentro de este ámbito debe ser un reto y una meta a alcanzar para mejorar la

asistencia y el servicio que reciben los pacientes con DCA, y para lograr los mejores resultados posibles que beneficien al paciente, su entorno y a toda la sociedad.

En el presente trabajo se ha abordado de forma exhaustiva la conciencia de déficit de los pacientes con DCA. En el primer estudio se ha llevado a cabo una revisión sistemática sobre la literatura publicada en las dos últimas décadas, centrada especialmente en tres aspectos relevantes que han suscitado gran volumen de estudios: la relación entre la conciencia de déficit y el rendimiento en diferentes procesos cognitivos (especialmente memoria y función ejecutiva); los programas de intervención diseñados específicamente para abordar la conciencia de déficit y la eficacia de los resultados obtenidos; y por último los estudios que han explorado la relación entre la mejora en conciencia de déficit y la independencia funcional en las actividades de la vida diaria de dichos pacientes. En el segundo estudio se ha presentado un programa diseñado específicamente para mejorar la conciencia de déficit de los pacientes con DCA. Comparados con un grupo control, los pacientes que reciben el programa aumentan significativamente su nivel de conciencia en las tres dimensiones exploradas (lesión, déficit y discapacidad), especialmente aquellos pacientes que tenían niveles más bajos al inicio del mismo. En tercer lugar, se ha explorado la relación entre la mejora en conciencia de déficit y la mejora en términos de independencia funcional de los pacientes con DCA. Los resultados obtenidos muestran que la mejora en conciencia de déficit alcanzada con el programa de intervención, así como en la muestra global de pacientes, se relaciona con una mejora en términos de funcionalidad, considerando ésta como el grado de independencia en las actividades instrumentales de la vida diaria.

El primer paso para un abordaje adecuado de la conciencia de déficit es contar con herramientas e instrumentos de evaluación adecuados.

Diferentes aproximaciones y técnicas se han desarrollado en las últimas décadas con este acometido, lo cual ha generado la disponibilidad de una amplia variedad de instrumentos y escalas que dificultan el consenso (Brown et al., 2019) y la posibilidad de comparar de forma precisa los resultados de las investigaciones realizadas. Así mismo, la mayoría de estas aproximaciones se han centrado en el componente neuropsicológico y en mayor medida concretamente en el aspecto metacognitivo de la conciencia de déficit, recibiendo una menor atención el aspecto emocional y psicológico. Sin embargo, considerar estos mecanismos subyacentes a una afectada conciencia de déficit resulta fundamental para un abordaje completo de la misma. Poder analizar, diferenciar y relacionar el componente psicológico presente en una conciencia de déficit afectada, el cual se manifiesta habitualmente en términos de negación, con el uso de falsas atribuciones o la presencia de anosodiaforia (apatía o reacción de indiferencia presentada por los pacientes ante la presencia de un daño cerebral), resulta fundamental para una compresión completa del estado del paciente.

Por lo tanto, una conciencia de déficit afectada puede tener en parte un origen neurológico, y deberse a los efectos propios de la lesión, y por otra un origen psicológico que provoca una negación de los déficits y la discapacidad. Un paciente puede estar situado en cualquier lugar a lo largo de este continuo y algunos de ellos pueden mostrar síntomas mixtos que fluctúan con el tiempo. Por esta razón, abordar estos dos aspectos en la evaluación y también en la intervención de la conciencia de déficit en pacientes con DCA, es realmente importante para las investigaciones futuras y el progreso de la práctica clínica.

El trabajo de investigación con población clínica resulta complicado, y en particular el DCA es una patología compleja, formada por diferentes etiologías, diferentes grados de severidad de la lesión, y afectación a

distintos niveles (motor, cognitivo, conductual y emocional), lo que dificulta su abordaje y la especificidad de los resultados. En este sentido, una de las limitaciones más importantes del trabajo presentado está relacionada con el perfil de pacientes considerado. La muestra de los estudios experimentales incluidos contiene pacientes con daño cerebral de diferentes etiologías (fundamentalmente accidentes cerebrovasculares y traumatismos craneoencefálicos), y con distintos niveles de severidad. Este hecho permite por un lado generalizar los resultados a un sector mayor de la población con DCA, sin embargo, impide la posibilidad de conocer si los diferentes perfiles de pacientes se comportan de forma específica pudiendo mostrar resultados diversos.

El presente trabajo, aunque no exento de limitaciones, posibles mejoras y retos para el futuro, supone un abordaje extenso y aplicado de la conciencia de déficit en pacientes con DCA. Este trabajo permite conocer las características y necesidades de los pacientes que, tras sufrir un daño cerebral presentan una afectación de la conciencia de déficit, y especialmente saber cómo abordarla en términos de evaluación y, más importante, de intervención específica sobre la misma. Lograr un aumento de la conciencia de déficit tendrá un impacto significativo en el paciente y su entorno, influyendo en el proceso rehabilitador y en los resultados del mismo a nivel de independencia funcional en las actividades de la vida diaria, con la influencia que esto supone en su calidad de vida.

## **Abstract**

### **1. General introduction**

Suffering an acquired brain injury (ABI) has significant consequences for patients and their environment. The most common sequelae of an ABI mainly affect motor, behavioural, cognitive and emotional domains, and have important impacts in patient's daily living.

Likewise, it is common that many of these patients are not aware of the deficits that the injury has caused, and especially of the disability that it generates, showing what is known as impaired self-awareness (SA) (also called anosognosia) (Ownsworth et al., 2007). Impaired SA is not an exclusive feature of patients with ABI, it is also present, and has relevant effects, in other pathologies such as neurodegenerative diseases (Gainotti, 2018), psychiatric diseases (Poletti et al., 2012), or substance abuse disorders (Le Berre & Sullivan, 2016).

Patients with low SA show less motivation towards the rehabilitation process, set unrealistic goals, and can perform actions that pose a risk to themselves and to others (Malec & Moessner, 2000; S. M. Smeets et al., 2015). Likewise, a low SA is associated with worse rehabilitation outcomes and a lower degree of functional independence (Ekstam et al., 2007; Ownsworth & Clare, 2006).

Exploring anatomical correlations associated with an impaired SA has generated great interest. This characteristic has traditionally been associated with lesions in the right hemisphere of the brain and, in particular, with areas that comprise anterior regions. However, in recent decades, and due to the popularization of the use of neuroimaging techniques that allow for the

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analysis of brain function, in terms of brain connections, the evidence suggests that deficits in SA are associated with disconnections between relevant integrated regions in different brain networks. These could include the dorsal prefrontal cortex (Schmitz et al., 2006) and the fronto-parietal cortex (Ham et al., 2014), although these studies are still inconclusive. In addition, the latest models and visions regarding SA, which consider not only its neuropsychological component, but also the importance of psychological and emotional aspects, suggests that the entire phenomenon probably requires more distributed networks that also integrate subcortical and brain stem regions (Philippi et al., 2012).

The interest in the study of SA as an important factor in the cognitive status of patients with ABI has grown in recent decades, leading to different theories and explanatory models. The first one, known as the *Pyramid Model* (Crosson et al., 1989), divides SA into three hierarchical levels: the intellectual awareness (patient's ability to recognize their deficits or impaired functions) is located at the base; secondly, the emerging awareness (ability to perceive and describe the own difficulties at the time they are occurring); and thirdly the anticipatory awareness, which refers to the ability to predict that a difficulty or problem may occur as a result of the deficit.

A second model, the *Dynamic Comprehensive Model of Awareness* (Toglia & Kirk, 2000) emphasizes the interaction between two main components of SA: the metacognitive, which refers to general knowledge about one's abilities; and online, in relation to awareness of performance *in situ* during the task completion. Finally, the *Biopsychosocial Model of Awareness* (Ownsworth, Clare, et al., 2006), considers different factors associated with SA: neuropsychological, psychological and social. The former are related to the damage itself, which at the neuropsychological level causes the SA impairment and difficulties in daily living. Psychological factors

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include emotional aspects related to the disease, the presence of denial, as well as the coping style. Finally, social factors include interactions with other people (family, friends and clinicians) and also other cultural aspects such as stigma associated with the disease.

All the models presented have provided relevant information to increase the knowledge about SA in patients with ABI. Nowadays, it is necessary to consider the differences between the metacognitive and online components when developing and selecting SA assessments scales, and also with the aim to intervene on it. Likewise, distinguishing between neuropsychological and emotional or psychological aspects linked to an impaired SA is essential to precisely address this aspect that has proven to be significant in the rehabilitation process.

However, SA is not an isolated process, independent of other cognitive functions. SA should be addressed considering its metacognitive component. Metacognition refers to the ability to represent and access our own cognitive processes, being this ability crucial for understanding and optimizing how we learn, remember, and perform, allowing us to avoid strategies that have not worked for us in the past, and keep those that actually worked (O'Leary & Sloutsky, 2019). Thus, it is essential to know how it relates to other higher order cognitive processes, primarily memory and executive functions. On the one hand, some studies have found direct relationships between SA and memory measures (Long et al., 2014). Other studies, however, have deepened the relationship between executive function and SA, showing relationships both at a general level (Hart et al., 2005), as well as in specific processes such as cognitive flexibility (Bivona et al., 2008; Ciurli et al., 2010) and inhibition (Bogod et al., 2003).

From the early descriptions of these relationships, subsequent studies have used regression analysis to characterize the predictive value of some

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cognitive functions in SA. First, it has been suggested that memory performance could predict the level of SA in patients with ABI (Noé et al., 2005; Zimmermann et al., 2017). In addition, performance in executive functions, particularly in monitoring and cognitive flexibility processes (Morton & Barker, 2010; Noé et al., 2005; Zimmermann et al., 2017), inhibition (Bogod et al., 2003) and categorization (Goverover, 2004) also seem to be a good predictor of SA level.

The first step in addressing any cognitive process, requires to be able to perform a correct assessment of it. Numerous instruments and scales have been developed to accurately measure SA. They can be classified into three main groups based on the perspective used to conduct the assessment:

1. Compare patients' self-ratings on questionnaires of functional abilities, with the informants' ratings (friend, family member or clinicians) in a homologous questionnaire version. The most widely used scale within this type of evaluation system is the Patient Competency Rating Scale (PCRS) (Prigatano et al., 1986), although there are others among we can highlight the Awareness Questionnaire (AQ) (Sherer et al., 1998).
2. Conduct a semi-structured interview about the patient's perception of his/her condition, abilities, perceived difficulties, or goals setting. Subsequently, using his clinical judgment the professional qualifies whether patient's SA fits reality. The most widely used scale is the Self-Awareness of Deficits Interview (SADI) (Fleming et al., 1996).
3. Compare the patient's self-rating with their performance in specific *in vivo* tasks, such as performance in neuropsychological tests. In this type of assessment the patient makes an estimation of his execution in a certain task and then it is compared with the real performance.

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Considering the metacognitive or the online aspect of SA is critical for selecting one assessment scale or other. While the instruments corresponding to the first two groups assess the patient's knowledge and beliefs about his condition, difficulties and general performance (intellectual awareness of the model of Crosson et al., 1989), the third of them is based on the online SA aspect (emerging and anticipatory awareness) (Brown et al., 2019).

In the present work we have primarily addressed the metacognitive component of SA. The two mentioned methods that assess SA from this perspective present advantages and limitations. The literature has showed that comparing the patient's self-rating with that of a close relative could be inappropriate, especially in cases with a recent brain injury, because the latter may also have an opinion not really adjusted to reality, due to their emotional state and the difficulty of accepting what happened (Fleming et al., 1996; Prigatano et al., 2005). However, regarding the other assessment method, the clinician's knowledge about the patient is usually more limited than one from a relative or friend, especially about patient status before the injury, and in current performance in real contexts, outside the rehabilitation environment. For this reason, if the clinician is who judges the patient's degree of SA, he must be part of his rehabilitation process having an extensive knowledge about patient's condition and evolution.

In the studies included in this work, an *ad-hoc* scale developed in the National Centre for Brain Injury Treatment (CEADAC) has been used. The scale is administered in a semi-structured interview format. Scores are based on the clinician's assessment guided by the patient's responses. The scale is formed by three main areas. The first one, awareness of Injury, is based on the score (from 0 to 6) that the clinician gives depending on whether the patient is able to acknowledge having suffered a brain injury or not, either

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spontaneously or in response to the clinician's questions. The awareness of deficit score (from 0 to 12) depends on whether the patient spontaneously refers to suffering from different physical, sensory and cognitive deficits or requires help or examples to recognise them, or by contrast, actually ignore their deficits. Finally, the awareness of Disability dimension asks the patient about their ability to currently perform a series of activities (i.e. driving, cooking dinner or living alone) and is scored (from 0 to 12) based on whether their answers are in line with reality or not. Therefore, considering the three dimensions, the maximum score that a patient can obtain in the scale is 30 indicating full awareness of having sustained a brain injury, its consequences and the disability it causes.

The *ad-hoc* scale has a format similar to the SADI, however, this scale was developed for a best adjustment of patient's characteristics (usually close injury), by including the awareness of the lesion section, which is most commonly impaired in these initial phases. In addition, it has a higher scoring range that allows a more specific final result.

In patients with ABI, impaired SA has an important impact in their rehabilitation process and its benefits, so a specific SA approach has become a priority element in intervention programmes. There are many techniques that have been used to improve SA, including psychoeducation, different types of feedback, comparing the patient's self-ratings with the real task performance, behavioural therapy and psychotherapy (Lucas & Fleming, 2005). In the literature, different intervention programmes have been designed and implemented and, through the use of some of these techniques, have proven to be effective in increasing patient's SA (Leung & Liu, 2011; Schrijnemaekers et al., 2014). Feedback is the most commonly used technique (Schmidt et al., 2011); it can be provided directly by the therapist, who describes the positive and negative aspects of the patient's

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performance in a task; or in a group intervention format, in which the other patients involved also collaborate in the feedback provision. In addition, some studies have used video recordings about the patient's own execution.

The selection of the more appropriate techniques to include in the SA intervention programme of a patient with ABI, should be done according to Fleming & Ownsworth, (2006), regarding the more relevant factors (neuropsychological, psychological and social) in the profile of each patient (Ownsworth, Clare, et al., 2006). For example, the use of feedback and the execution of real and structured tasks would be particularly effective in patients with executive problems that are influencing the lack of SA. On the other hand, those patients who deny their deficits, due to underlying psychological and emotional mechanisms, could benefit to a greater extent from an approach based on a good therapeutic alliance and from the use of psychoeducation, psychotherapy and the promotion and reinforcement of acceptance of change.

Mostly, research that implements a specific intervention programme for improving SA, assesses its success in terms of the increase achieved over it. However, the final goal of any rehabilitation programme should be to reach greater patient's functional independence, that is, greater autonomy in daily living activities. This relationship between SA and functional independence has been studied, finding that those patients with adjusted SA, achieve better results after rehabilitation (Ownsworth & Clare, 2006), being more independent in daily living instrumental activities (Giles et al., 2019).

In a recent review, Engel, Chui, Goverover, & Dawson, (2017) concluded that patients who take part of a specific intervention programme in SA improve in untrained activities similar to those included in the intervention (close transfer), as well as in different ones, more related to

daily living activities. These results suggest that the benefits induced by the specific intervention on SA can be partially transferred to activities of daily living, thus setting a relationship between the SA improvement and the degree of functional independence of patients with ABI.

## **2. Objectives**

This research has the global aim of addressing the concept of SA in ABI patients, and go deeper into the importance of considering the relevance of implementing specific intervention programmes in the context of the global rehabilitation process. Thus, the entire research is presented through three independent although related studies, each of them with specific objectives and hypothesis.

The general objective of the first experiment was to perform a systematic review of the literature focused on the role of SA in the rehabilitation of patients with ABI. Before a first conceptualization of SA, the specific objectives of the systematic review were focused on evaluating the state of the literature in three relevant aspects of interest: the relationship between SA and cognitive functioning, specific intervention programs for SA and the relationship between SA status and daily living functionality.

The aim of the second study was to develop an intervention programme in SA for patients with ABI, as well as test its efficacy. Considering the most previously used techniques and procedures, and reflecting on the strengths and limitations of these programs, the first specific objective of this study was to design a specific intervention programme, including those techniques that had proved their efficacy. Consequently, the second objective was to implement this specific

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intervention programme in a group of patients who were involved in a global rehabilitation process in the CEADAC. Finally, the third specific objective was to evaluate the efficacy of the intervention programme by comparing this group of patients with a control group, formed by patients who also received a global rehabilitation but with no specific SA intervention. Importantly, a major aim of the work was to provide a neat description of the intervention programme, including how it was developed, the amount of sessions included, the specific tools and material employed in each session, and the strategies implemented in the general process, among other important details.

The major objective of the third study was to explore the potential relationship between SA and daily living functionality of patients with ABI. The final goal of any rehabilitation programme for patients with ABI should be to make them as independent as possible in their daily living activities. Previous literature had shown that intervening in SA could be an effective strategy to improve functionality and autonomy in these patients. Once we have studied the results of implementing an intervention programme on SA, we considered essential to explore whether the increase of SA would extend to patients' functional outcome, enhancing their functionality in the activities of daily living.

### **3. Results**

#### **3.1. First study**

The results obtained showed that SA considered as a metacognitive process is linked to other higher order cognitive processes such as executive functions (Bogod et al., 2003; Ciurli et al., 2010; Goverover, 2004; Hart et al., 2005; Morton & Barker, 2010) and memory (Long et al., 2014; Noé et al., 2005; Zimmermann et al., 2017).

In addition, it has been possible to verify that in the last decades different research had been carried out with the aim of designing and implementing specific intervention programmes on SA, and have proven their effectiveness (Fleming & Ownsworth, 2006; Leung & Liu, 2011; Lucas & Fleming, 2005; Schrijnemaekers et al., 2014). The techniques used vary between the different approaches, being the most common psychoeducation, different types of feedback, comparison of self-rating with real performance in a task, behavioural therapy and psychotherapy.

Given the need to evaluate the success of an SA intervention in terms of functional improvement, of the eleven studies that to date have explored this relationship, seven found significant correlations between SA improvement achieved with the intervention programme, and better functional outcomes in the activities of daily living (Goverover et al., 2007; Malec & Moessner, 2000; Ownsworth & McFarland, 2004; Ownsworth et al., 2000; Skidmore et al., 2018; Tham et al., 2001; Villalobos et al., 2019).

### **3.2. Second study**

The second experiment, presented a specific intervention programme developed to increase SA in patients with ABI, within a comprehensive rehabilitation programme. The results obtained showed that patients who received the specific SA intervention programme exhibited a significant improvement in SA compared to patients in the control group. Likewise, it was found that this improvement was observed in all SA dimensions explored: injury, deficit and disability.

Finally, it was observed that patients with a lower initial level of SA before the intervention, were those who showed a greater degree of improvement after being involved in the rehabilitation programme.

### **3.3. Third study**

First, results showed that there was a significant difference in the degree of functional independence between both groups in the assessment performed after the intervention. Accordingly, the patients receiving the specific intervention programme showed a greater degree of functional independence. To confirm that these changes in SA achieved with the specific intervention were related to functional improvement, the relationship between the degree of improvement in SA and the degree of improvement in functional independence was explored. The results showed a marginal correlation, showing a potential relationship, which suggested that patients with greater SA improvement (after the intervention programme) possibly exhibited greater functional improvement after the rehabilitation process.

Then, we explored whether patient's level of SA prior to the intervention programme could influence the relationship between its improvement and functional enhancement. For that purpose, the relation

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between SA and functional improvement, controlling the effect of pre-treatment SA scores was explored. The results of this analysis showed a significant positive correlation, suggesting that patients with low initial level of SA, even experiencing significant improvements after the intervention programme, do not reach the required level to experience a substantial improvement in their functional outcome.

Finally, this relationship was also studied with the whole sample of patients, showing that the enhancement in SA (induced or not by the specific intervention programme) was related to the increase in the degree of functional independence.

## **4. General discussion**

ABI is a fact that significantly affects our society. According to data from the World Health Organization (WHO), this disease represents the third cause of death and the first cause of disability in adults. Recent data from European countries like the United Kingdom reveals that ABI incidence has increased by 10% over the past decade. The development of knowledge within this field must be a challenge and a goal to achieve in present and recent future, in order to improve the care and service that patients with ABI receive, and to achieve the best possible results that benefit patients, their environment and the entire society.

In the present work SA of patients with ABI has been comprehensively addressed. In the first study, a systematic review of the literature published in the last two decades has been carried out, especially focused on three relevant aspects that have led to a large volume of studies: the relationship between SA and performance in different cognitive processes (especially

## *Abstract*

memory and executive function); intervention programmes specifically designed to address SA and the results obtained; and finally the studies that have explored the relationship between improvement in SA and functional independence in the daily living activities. In the second study, a programme specifically designed to improve SA of patients with ABI has been presented. Compared to a control group, patients receiving the intervention programme significantly increase their level of SA in the three dimensions explored (injury, deficit and disability), especially those patients who had lower levels at the beginning of it. Thirdly, the relationship between improvement in SA and improvement in terms of functional independence of patients with ABI has been explored showing that the improvement in SA achieved with the intervention programme, as well as in the global sample of patients, is related to an improvement in terms of functionality, considering this as the degree of independence in the instrumental activities of the daily living.

The primary step to correctly approach SA is to have suitable assessment tools. Different approaches and techniques have been developed in recent decades with this aim, which has generated the availability of a wide variety of instruments and scales that reveal a lack of consensus (Brown et al., 2019) and difficult the possibility of comparing the different research results. Likewise, most of these approaches have focused on the neuropsychological component of SA and specifically on its metacognitive aspect, with the emotional and psychological aspect receiving less attention. However, considering these mechanisms underlying an impaired SA seems to be critical for a complete approach. Being able to analyse, distinguish and relate the psychological component of an impaired SA, which usually is manifested in terms of denial, with the use of false attributions or the presence of anosodiaphoria (apathy or indifference reaction presented by patients before the presence of brain damage), is central for a complete understanding of the whole patient's condition.

## *Abstract*

Therefore, an impaired SA may partly have a neurological origin, and results from the effects of the injury itself, and also a psychological origin that causes a denial of deficits and the associated disability. Any patient can be located anywhere along this continuum and some of them may show mixed symptoms that fluctuate over time. For this reason, addressing these two aspects in the evaluation and also in the SA intervention of patients with ABI is essential for future research and the progress of clinical practice.

Accurate research with any clinical population is complicated, and ABI in particular is a complex pathology, consisted of different etiologies, wide range of lesion severity, and involvement of different domains (motor, cognitive, behavioural and emotional), which makes its approach challenging and the specificity of the results scarce. In this sense, one of the most important limitations of the presented research is related to the profile of patients considered. The sample included in the experimental studies consists of patients with ABI of different etiologies (mainly strokes and traumatic brain injury), and with different levels of severity. This fact allows to generalize the results to a larger part of the population with ABI; however, it prevents the possibility of considering whether different profiles of patients may obtain distinct effectiveness of intervention programmes and their influence in patients' functional independence.

The present work, despite limitations, allows for improvements and challenges for the future, and implies an extensive and applied approach to SA in patients with ABI. This work allows us to investigate the main characteristics of those ABI patients who present an impaired SA, and especially how to address them in terms of assessment and specific intervention. Reaching an improvement in SA will have a significant impact on patient's life and their environment, influencing the rehabilitation process

*Abstract*

and its results on functional independence in the activities of daily living, with an important effect in their quality of life.

*Abstract*

## **Chapter I. Introduction**

### **1. Brief history and terminology**

The term “anosognosia” was employed for first time by the French neurologist Joseph Babinski (Babinski, 1914) to describe patients with a severe disability that seemed to be unaware of the presence of their deficit. This first description was related with two patients who had suffered a stroke in the right brain hemisphere and presented left-sided hemiplegia that was accompanied by unawareness of their paralysis. Previously, Gabriel Anton had described the existence of cortical deafness and cortical blindness illnesses in patients with specific brain damages, characterized also for the unawareness of these important disabilities (Anton, 1899).

Nowadays, the term anosognosia is used for describing the absence of awareness of deficit in different neurological pathologies. It may include motor deficits (hemiplegia), sensory disorders (cortical deafness and blindness), spatial deficits (unilateral neglect), language disorders (sensory aphasia), memory disturbances, dementia, and even personality changes (Gainotti, 2019). Importantly, anosognosia can be selective because it commonly affects a single deficit even when patients are affected by multiple impairments. This phenomenon of double dissociation between disorders of which the patient is aware and unaware, can mean that in anosognosia, brain injury can selectively impact the self-monitoring process of one specific physical or cognitive process rather than affecting a general control function. Even though most early studies of anosognosia have focused on hemiplegia and other symptoms resulting from mainly focal brain lesions, in more recent times much more attention has been paid to anosognosia in the cognitive domain, derived from studies on patients with

more diffused and distributed lesions, or even with neurodegenerative disorders (e.g. Alzheimer Disease, (Perrotin et al., 2015).

Therefore, the current view of anosognosia refers to the impairment of a general ability known as "self-awareness" (SA), which is defined as the capacity that allows us to consciously perceive our own actions, abilities and mental states (Keenan, Gallup, & Falk, 2003). When this ability is affected by a brain injury, it is referred within a clinical context as anosognosia or "impaired self-awareness" (ISA), which implies a lack of knowledge about the changes in personal skills and abilities, and the implications of these changes for daily living and the future (Ownsworth, 2017).

There are differences between anosognosia and other related terms. Anosodiaphoria refers to the emotional reaction of indifference that many patients show in spite of having suffered a brain injury, so it is related with the apathy or lack of concern in relation to a condition. However, there is some overlap between these two phenomena, because people who are unaware of their deficits often present diminished emotional responses towards them. Nevertheless, impaired SA may be accompanied by preserved emotional reactivity to their deficits or symptoms. Although as the patient improves in SA, anosodiaphoria tends to diminish, some degree of anosodiaphoria may still be observed when the patient self-reports their deficits. Therefore, anosodiaphoria does not appear to be a method of coping, but rather a common part of the clinical condition (Prigatano, 2014).

## **2. Self-awareness in neurological pathologies**

The present work focuses on SA in patients with acquired brain injury (ABI). However, the impairment of the ability to be aware and recognize deficits and the associated disability also appears in other clinical populations.

In neurodegenerative diseases it is common that patients are not aware of the illness, as well as the deficit and problems that it causes (Gainotti, 2018). In Alzheimer, the most frequent neurodegenerative disease, anosognosia is a common clinical symptom even in the earliest stages, and its frequency increases with disease progression (Lehrner et al., 2015). In recent years, many studies have also investigated the lack of SA in mild cognitive impairment, which has been considered a prodromal stage of Alzheimer's disease. These studies show that impaired self-perception is also frequent in this initial stage, although considerable variability has been observed (Vannini et al., 2017). The fact remains that in Alzheimer's disease, this impairment in SA may be especially related to memory patient's difficulties to learn and retrieve episodic details. Thereby, the impairment in consolidating information about daily performance failures, can be at the base of the more evident SA deficits (Morris & Mograbi, 2013). In addition, in Parkinson disease, a large proportion of patients present impaired SA, specifically for cognitive and behavioural deficits (Orfei et al., 2018), which leads them to underestimate their degree of disability in activities of daily living (Leritz, Loftis, Crucian, Friedman, & Bowers, 2004).

Impaired SA is also a hallmark in schizophrenia. Lack of knowledge of the disease, of the psychotic symptoms, as well as the cognitive deficits, is one of the most characteristic features of this disease (Poletti et al., 2012). Likewise, it is widely recognized that this affection has a notable influence on cooperation with treatment and clinical outcome. As in the rest of the

pathologies, in these patients, awareness of the need for treatment is predictive of treatment compliance, prognosis and social and occupational functioning of patients (Buckley et al., 2007).

Likewise, addicted patients often present impaired SA. They do not tend to recognize the reality of the disease and minimize the physical, cognitive, psychological and social difficulties associated with chronic abuse. The consequences can have important implications in their treatment and rehabilitation. During active drug use, deficits in these processes may be associated with a reduced perception of the need for treatment, and once during rehabilitation, lack of SA on their own neuropsychological deficits may be associated with reductions in the motivation and involvement in the treatment and a higher feeling of control on the execution of risk behaviours (see Verdejo-García, Fernandez-Serrano, & Tirapu-Ustarroz, 2013 for a comprehensive review).

In particular, in patients with alcohol use disorder, the lack of SA affects cognitive deficits, especially with those related to episodic memory. At the beginning of withdrawal, alcoholics can ignore their memory deficits and overestimate their abilities, with the risk that this generates in their daily functioning and the progress of the disorder (Le Berre & Sullivan, 2016). Impaired SA has also been studied in patients with cocaine abuse, showing that people with less awareness and greater denial of disinhibition problems (e.g., impulsivity, mood instability) have in turn more trouble maintaining motivation when starting treatment. The results suggest that awareness interventions may be useful to prevent premature dropout from treatment and improve addiction intervention outcomes (Castine et al., 2019).

The present work focus on SA in patients with ABI, it refers to an injury caused to the brain after birth. The causes or etiology of ABI are multiple, being the most common: strokes (ischemic or haemorrhagic), traumatic brain injury, tumours and brain infections (encephalitis).

The effects of the brain injury can be wide ranging, and depend on a number of factors such as type, location and severity of injury. However, in most cases, brain injury involves a series of effects that significantly affect the life of the patient and his family. Among these consequences are: physical problems, behavioural effects, cognitive deficits, communication problems, emotional effects, etc.

One of such specific cognitive/emotional deficits is related with SA. Research shows that lack of SA is a common problem in individuals who suffer an ABI; and longitudinal studies further suggest that SA is more impaired immediately after injury and improves over time (Robertson & Schmitter-Edgecombe, 2015), which distinguishes impaired SA in ABI from impaired SA in other pathologies. In addition, specific interventions programmes increase this SA improvement (Schrijnemaekers et al., 2014).

Impaired SA following ABI usually results in decreased motivation, compromised safety due to unrealistic goals, and impaired judgment which affected negatively rehabilitation outcomes (Schmidt et al., 2011). In ABI population, research has shown that greater SA is related with favourable rehabilitation outcomes (Ownsworth & Clare, 2006). For these reasons, in patients with ABI where early rehabilitation is essential for the recovery of the patient, the specific approach to SA becomes highly relevant (Leung & Liu, 2011).

### **3. The study of anatomical correlation of impaired self-awareness**

The neuroanatomical correlation of impaired SA emerges as an interesting aspect of this phenomenon. Traditionally, impaired SA has been related with the right hemisphere, and especially with damage that involves anterior regions as frontal and temporal areas. Nevertheless, more recent studies have suggested that it does not correlate with lesions in specific brain regions, but with the extent and amount of lesions and, notably, the breakdown of important networks. Still, there are huge variability in the brain underpinnings reported the date, probably due to the complexity of SA and its multidimensional nature. Furthermore psychological factors which also contribute to the presence of impaired SA, are usually not considered in this investigations (Belchev et al., 2017).

Some studies using functional magnetic resonance imaging (fMRI) have explored the implication of important brain network in different features related with impaired SA. Schmitz et al. (2006) concluded that a more accurate self-referential insight was related to increased signal change in the right anterior dorsal prefrontal cortex (PFC), a network including the medial and right dorsal PFC. Moreover, emergent SA has been related with fronto-parietal control network (FPCN); in particular, the dorsal anterior cingulate cortex showed reduced functional connectivity and the anterior insula showed increased activity following errors (Ham et al., 2014). However, other hypothesis supports that SA is likely to emerge from more distributed interactions among brain networks that include the brainstem, thalamus, and posteromedial cortices. Philippi et al. (2012), in a case study with a rare neurological patient with extensive bilateral brain injury (including the insula, anterior cingulate cortex, prefrontal cortex, and the

medial temporal lobes), showed that, in spite of severe amnesia, patient's main aspects SA remained fundamentally intact.

Additionally, investigating the functioning brain regions associated to SA in other neurological pathologies could result in an interesting approach for the better understanding of the anatomical correlation to this construct. In cocaine addiction impaired SA of cognitive and motivational deficits seems to have a neural underpinning implicating striatum, orbital frontal cortex, and dorsolateral prefrontal cortex (Moreno-López, Albein-Urios, Martínez-González, Soriano-Mas, & Verdejo-García, 2017). In Alzheimer disease, Perrotin et al. (2015) found that impaired SA is due not only to functional changes within cortical midline structures involved in self-referential processes (orbitofrontal and posterior cingulate cortex), but also to disconnection between these regions as well as with the medial temporal lobe. These findings suggest that the lack of awareness in Alzheimer patients possibly results from a disruption of the communication within, but also between, the self-related and the memory-related brain networks.

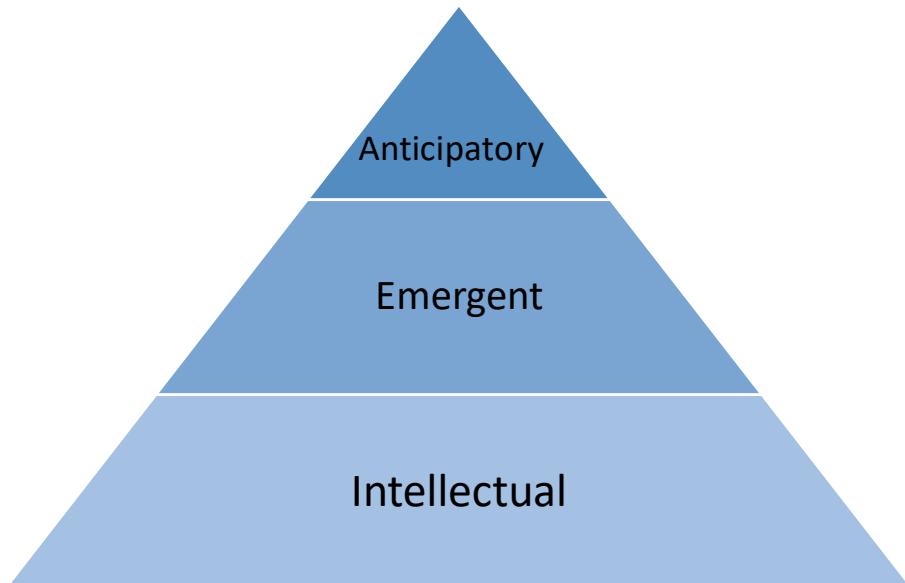
To draft conclusions on the neuroanatomical correlation of SA results a really complicated goal. The nature of this process and also the complexity of the brain functioning, suggest that it is not possible to limit to a specific number of brain areas the ability of be aware and recognise the difficulties, disability and their implications. However, further studies which address the research in terms of networks that involve cortical and subcortical areas, seem to be the most appropriate view to further knowledge.

#### 4. The multidimensional aspect of self-awareness: Conceptual models

In general, research on impaired SA in the different pathologies accords in considering that it is a complex construct formed by different aspects and dimensions, which can affect differently the patient's status. Several models have been developed to conceptualize SA, mainly focused on describing their different components or dimensions. Three models have been the most influent in the literature.

##### 4.1. The Pyramid Model

The first proposed SA model, called *The Pyramid Model* (Crosson et al., 1989), highlights its multidimensional aspect. It consists of three interdependent and hierarchical levels (See Figure 1).



**Figure 1.** Representation of Crosson et al., (1989) Model of awareness.

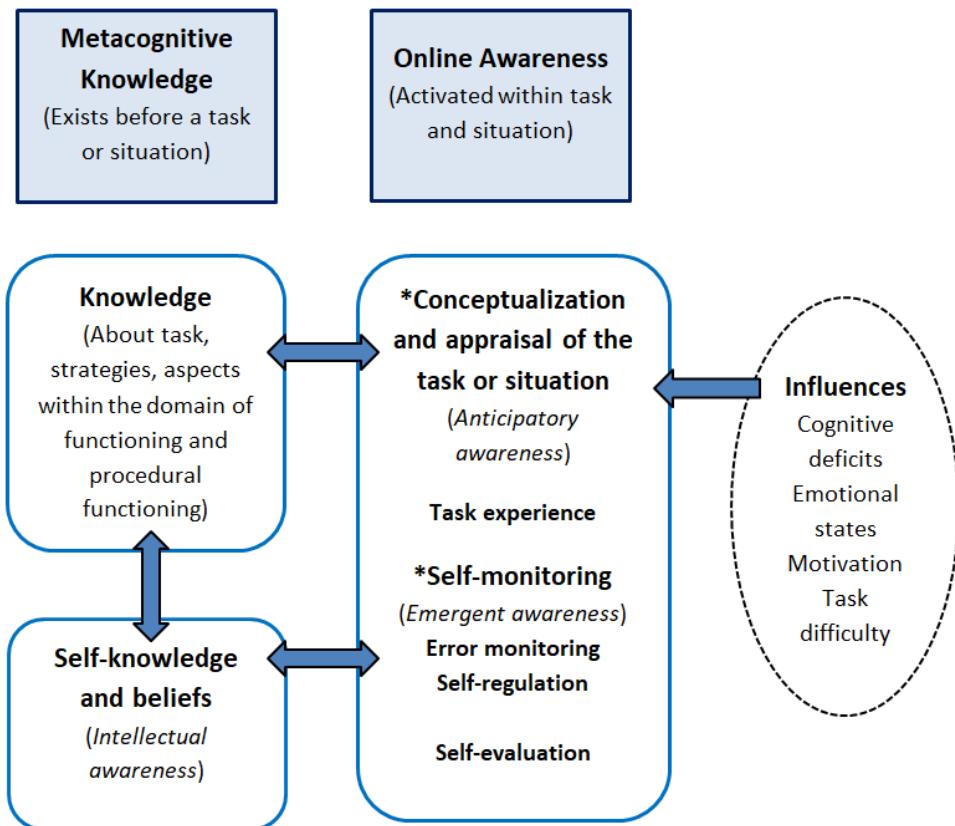
**Intellectual awareness** is at the bottom of the pyramid, it refers to the ability to recognize that a particular function or ability is impaired. It provides the foundation of the following two others awareness. **Emerging awareness**, on the second level, refers to the ability to monitor ongoing performance and recognize problems or errors when they occur. The patient may acknowledge the existence of a deficit but fail to recognize errors unless someone else points them out. At the top of the pyramid is anticipatory awareness. **Anticipatory awareness** is the ability to anticipate that a difficulty or problem may occur as a result of the deficit. Intellectual and emergent awareness are prerequisites for anticipatory awareness. Thus, an individual may be able to acknowledge and recognize errors while performing a task but be unable to use this knowledge to predict the consequences of the deficit or anticipate difficulties in advance.

Despite being a model developed many years ago, its influence in the subsequent approach to SA has been critical. In addition to making a theoretical approach to the phenomenon, the authors proposed its usefulness for the assessment as well as the intervention of SA. The authors pointed out that the intervention techniques used with each patient must conform to the degree of SA impairment and to the level or dimension that is principally affected. Therefore, they noted that it is necessary to evaluate the patient's level of SA both in the planning of the rehabilitation, and in the course of the intervention, to adapt the approaches according to the changes in patient's SA level. The goal is that patients could be able to reach the highest possible level of SA of their deficits and disability, and implement the necessary compensatory strategies (Crosson et al., 1989).

#### **4.2. Dynamic Comprehensive Model of Awareness**

The second explanatory model of SA, called *Dynamic Comprehensive Model of Awareness* (DCMA) (Toglia & Kirk, 2000), does not suggest a hierarchical structure. However, this model focuses on the relationship between SA and different aspects of metacognition.

Toglia and Kirk model's discriminates between offline awareness, which is awareness that exists prior to a task, and online awareness, which is the awareness that exists during and directly after a task. Offline awareness is called metacognitive awareness. **Metacognitive awareness** includes knowledge and beliefs about the person's overall procedural performance, knowledge about task characteristics and strategies, as well as the person's perception of his or her own abilities and functioning. **Online awareness** is divided into two interacting components. One part of online awareness is the person's conceptualization and appraisal of the task or situation (comparable to anticipatory awareness of Crosson's model). The second part of online awareness is called self-monitoring (comparable to emergent awareness) and it is related with the possible change in their beliefs and perceptions after the experience in a task. In addition, in this model self-monitoring is further conceptualized as consisting of two parts: error-monitoring and self-regulation. Error-monitoring is the ability to recognize errors, while self-regulation is the ability to adjust performance. The Dynamic Comprehensive Model of Awareness also recognizes that outside influences may interact with SA, so SA may vary across situations and domains, and individuals' emotional responses to feedback may change throughout these components of SA (Robertson & Schmitter-Edgecombe, 2015). See Figure 2.



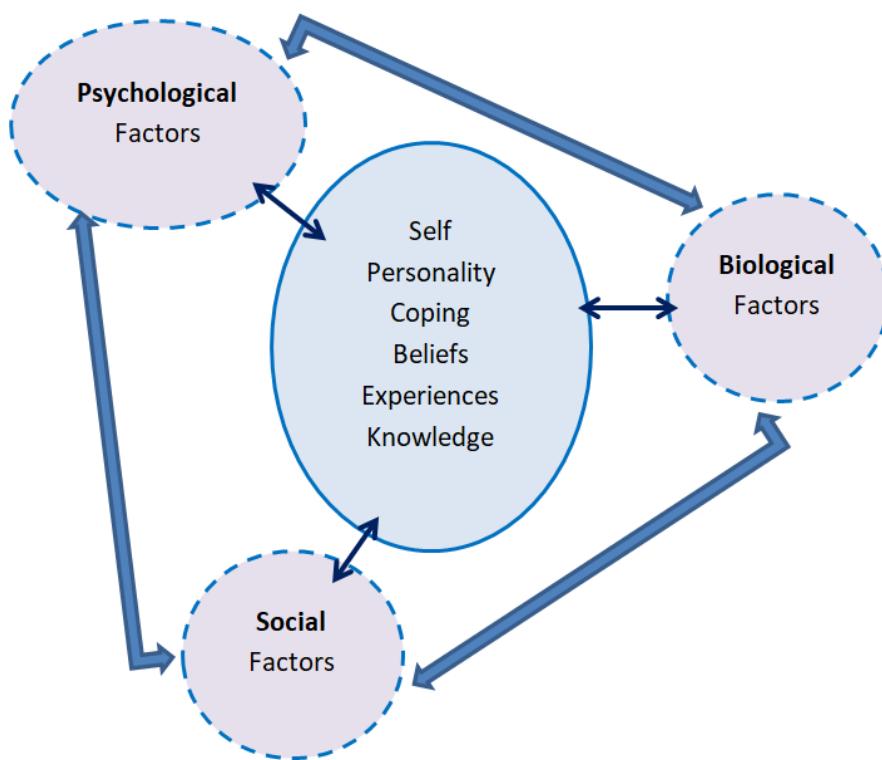
**Figure 2.** Simplified representation of the “Dynamic Comprehensive Model of Awareness” (Toglia & Kirk, 2000).

The *Dynamic Comprehensive Model of Awareness* is not necessarily independent from The *Pyramid Model*, and both are currently considered in the approach of SA from a clinical point of view. In this sense, the measure methods and the intervention techniques that have been developed in recent years to address SA in patients with ABI have focused on some aspects or dimensions of SA. This work and the studies included on it have been developed considering mainly the metacognitive dimension of SA.

#### **4.3. Biopsychosocial model of awareness**

This models aims to account for varied clinical presentations across the different patients with impaired SA. This framework pretends to cover key contributions of cognitive neuropsychological models and also consider the operation of psychological and social factors in SA problems. Previous models were more focused on describing and explaining the relation between the different components of SA; however this latter model focuses on addressing the different factors that influence the presence of impaired SA and its progress.

This biopsychosocial model integrates relevant factors at the **biological, psychological and social levels** (Ownsworth, Clare, et al., 2006). At the biological level, factors are related with neurocognitive mechanisms involved in impaired SA, including knowledge of global or selective physical, sensory or cognitive deficits, and also online awareness or self-monitoring of behaviour during performance. At the psychological level, factors include denial, coping style (i.e. avoidant coping or minimisation), and behavioural indications related with the emotional aspect of the situation. The social level refers to factors relate with interactions with others (family, friends and professionals) and also dimensions of experience such as stigma or exclusion, and the influence of social and cultural representations of the illness. See Figure 3.



**Figure 3.** Representation of the “Biopsychosocial model of awareness” (Ownsworth, Clare, et al., 2006) (FitzGerald et al., 2012).

The model proposes a dynamic interaction between the factors operating at each of the three levels, which influences and is influenced by subjective experience of self. It is suggested that across individuals, the relative contribution of factors operating at each level will change, which also happen when comparing different kinds of illness (this models is proposed to be considered not only for brain injury patients). Thus, for some individuals with specific SA impairments, these might predominantly be accounted by factors at the biological level; however, in neurodegenerative diseases, psychological and social factors would typically account for a greater amount of SA deficits.

One of the main intentions of the model is to help clinicians to address and intervene with patients with impaired SA. It could be useful to identify the specific factor, or set of factors, which might contribute to a given individual's presentation of impaired SA, and focus the intervention in approach this aspect. Recent studies are in line with this model, pointing out that knowing which factors are influencing impaired SA is essential to develop and choose the most accurate measurement tool (Brown et al., 2019).

## **5. The assessment of Self-awareness**

The assessment of SA is an important point of the neuropsychological evaluation of patients who have suffered ABI. Three main approaches to the assessment of SA have been traditionally considered (Brown et al., 2019). The first approach consisted on comparing patients' self-ratings on questionnaires of functional abilities to the informants' ratings (friend or family member or less frequently, a clinician) in a homologous questionnaire version. The second method is based on a semi-structured interview performed by a clinician, who consequently rates the patient's level of awareness based on a clinical judgement. Finally SA assessment can be performed comparing patient's self-ratings with objective functioning derived from their performance on neuropsychological tests.

Considering the metacognitive and online dimensions of SA is essential for a precise assessment, since different scales and questionnaires have been proposed to mainly measure one of these edges of this capacity. The following instruments are the most currently used to assess metacognitive aspect of SA from different perspectives:

### **5.1. Patient Competency Rating Scale (PCRS)**

The PCRS (Prigatano et al., 1986) is a 30-item questionnaire containing statements that describe physical, cognitive, emotional control and social abilities in terms of “how much of a problem” they present for the patient. For each item, ratings are derived from a 1-5 point Likert scale, in which 1 means “cannot do” and 5 “can easily do”. Equivalent forms of the questionnaire are administered to the patient and a significant other. The informant’s total score is then subtracted from the patient’s total score, providing a measure of patient-informant discrepancy. See Annex 1 for the patient form of the Scale.

The scale presents appropriate psychometric properties. The reliability (overall consistency of a measure) for PCRS total scores was  $r = 0.97$  for patients and  $r = 0.92$  for relatives (Prigatano, Altman, & O’Brien, 1990). Significant test-retest correlations were reported for 27 (patient sample) and 28 (informants) of the 30 items (Leathem, Murphy, & Flett, 1998). Internal consistency has proven strong for both patient ratings (Cronbach’s alpha=0.91, n=55) and relatives ratings of patients (Cronbach’s alpha =0.93, n=50) (Fleming et al., 1996).

### **5.2. Awareness Questionnaire (AQ)**

The AQ (Sherer et al., 1998) is a 17-item instrument in which patients are asked to rate how well they perform a variety of activities “as compared to before the injury”, with responses ranging from 1 (much worse) to 5 (much better). A parallel version with appropriately modified wording allows family members or other collateral persons to rate the patient on the same items. The scale assesses SA in three different dimensions: cognitive, behavioural/affective and motor/sensory. The total score for family or clinician is subtracted from the total score for the patient; a larger difference indicates greater impairment. See Annex 2 for the patient form of the Scale.

Related with psychometric properties, reliability studies of the AQ have revealed internal consistencies (Cronbach's alpha) of 0.88 for both patient and family ratings. Test-re-test reliabilities have not been reported (Sherer, Hart, & Nick, 2003).

### **5.3. Self-Awareness of Deficits Interview (SADI)**

The SADI (Fleming et al., 1996) is a semi-structured interview with three subscales assessing: SA of deficits; SA of functional implications of these changes and ability to set realistic goals. The scale is filled by the clinician who knows the patient's level of impairment. A 4-point scale is used, whereby the interviewer assigns a score of 0–3 for each subscale (0 means intact SA and 3 means severe SA impairment). The three subscale scores can be added together to provide a SADI total score, ranging from 0–9, with higher scores indicating lower metacognitive awareness (See Annex 3 for the complete Scale). Psychometric properties of SADI show that it has a good reliability (fair agreement between the raters on the three sections of the with intra-class correlation coefficient values of 0'78, 0'57 and 0'78, respectively, and 0.82 on the three subsections combined) (Fleming et al., 1996), however, little validity information is available (Smeets, Ponds, Verhey, & Van Heugten, 2012).

A systematic review of instruments for assessing SA in patients with ABI found that these three scales (PCRS, SADI and AQ) have the best psychometric properties among the whole set of available measures (Smeets, Ponds, Verhey, & Van Heugten, 2012). There are important differences between them (See Table 1 for main characteristics and differences on the three scales). The three scales consider SA in different dimensions (i.e. cognitive, behavioural, emotional, physical or social), but only the AQ really allows to make independent judgements of them. Other different aspect is that the PCRS assess patient's competencies just in the

present, whereas the AQ asked patients to compare current and previous functioning. The SADI is conceptually different from the PCRS and AQ and includes questions about the implications of the deficits for living at present as well as in the future (patient's ability to set realistic long-term goals). It is necessary to know that all this instruments are mainly focused on measure intellectual/metacognitive awareness, thus others tools should also be used to gain a complete view of a patient's SA deficits.

Scale	Method	SA component	Dimensions	Focus (Future consideration)
PCRS (Prigatano et al., 1986)	Self-other rating discrepancy	Intellectual	YES Physical, cognitive, emotional and social	Pre and post injury functioning in daily activities NO
AQ (Sherer et al., 1998)	Self-other rating discrepancy	Intellectual	YES Cognitive, behavioural/affective and motor/sensory	Post injury functioning in daily activities NO
SADI (Fleming et al., 1996)	Clinician rated	Intellectual	NOT SEPARABLE Cognitive, behavioural, physical and emotional	Post injury deficit and implications of disabilities NO

**Table 1.** Main characteristics of principals SA assessment scales.

Selecting the most appropriate scale for measuring metacognitive awareness is not exempt of difficulties either. Studies using self-rating versus others-ratings assume the informants provide a more objective understanding of the abilities and difficulties than the patient. Important critiques of this method highlight that this aspect can impact on results, since the burden and stress that family members suffer are known to affect their reports (Prigatano, Borgaro, Baker, & Wethe, 2005). Still, family or close others are likely to have the best knowledge of patient's daily and premorbid

functioning, so if the clinician is the responsible for rating patient's awareness, must rely on them if need more information. In general, patient/clinician discrepancies appeared to be more valid measures of SA early after ABI than patient/family discrepancies (Sherer et al., 2003).

In this sense, the SADI does not use discrepancy scores and instead relies on the rating of a close clinician that assesses SA based on information provided by the patient in the interview, their knowledge of the patients and if necessary, other collateral information. Additionally, the SADI uses open questions that allow for the examination not only of awareness of deficits, but also awareness of the ability to set realistic goals. Finally, it has been demonstrated that it better correlates with executive function measures (Bogod et al., 2003). Because of these properties the SADI has been proposed as a more complete measure of SA than the AQ and PCRS (Richardson, McKay, & Ponsford, 2014).

In all the studies included in this work, it has been used an *ad-hoc* scale developed in CEADAC (Centro de Referencia Estatal de Atención al Daño Cerebral/ National Centre for Brain Injury Treatment), for a best adjustment of the centre patient's characteristics (usually close injury). The scale shares the approach and structure of SADI, being also administered in a semi-structured interview format. Scores are based on the clinician's assessment guided by the patient's responses. Thus, it overcomes the drawbacks associated to the assessment method previously discussed here in regard with the accuracy of patients' status reports provided by relatives. In comparison with the SADI, it has been purposely designed with the aim to suit the characteristics of patients who are at early stages of rehabilitation, thus our *ad-hoc* scale contains a first section on awareness of lesion, an important aspect considering the kind of patients involved in the centre and in our investigations. An also, the range score is wider (from 0 to 30, while

the SADI range from 0 to 9), that allowing for a more specific result (see the completed scale, Spanish version, in the Annex 4).

The scale is formed by three main areas: awareness of Injury, awareness of deficit and awareness of disability. This structure is based on previous studies that differentiate between the awareness of the deficits themselves and the awareness of the functional implications of such deficits (Giacino & Cicerone, 1998). The **Awareness of Injury** dimension is based on the score that the clinician gives depending on whether the patient is able to acknowledge having suffered a brain injury or not, either spontaneously or in response to the clinician's questions. As has been previously mentioned, this dimension is a novelty regarding previous divisions established by other authors. It was included in order to take account of the degree to which the patient with ABI is aware of having suffered brain damage, a factor that could be considered a prerequisite for the development of a global SA. It ranges from 0 to 6. The **Awareness of Deficit** dimension, scores depends on whether the patient spontaneously refers to suffering from different physical, sensory and cognitive deficits requires help or examples to recognise them or by contrast, actually ignore their deficits. This dimension ranges from 0 to 12. Finally, the **Awareness of Disability** dimension asks the patient about their ability to currently perform a series of activities (driving, cooking dinner or lunch, doing house chores, looking after a young child, working or studying and living alone) and is scored based on whether their answers are in line with reality or not. This dimension also ranges from 0 to 12. Therefore, considering the three dimensions, the maximum score that a patient can obtain in the scale is 30 indicating full awareness of having sustained a brain injury, its consequences and the disability it causes.

Although the scale has not been validated yet, in the first experimental study showed in the present work that has been performed using it (Chapter

IV: Villalobos, Bilbao, Espejo, & García-Pacios, 2018), it was compared with SADI measures. Using correlation analysis, results showed significant negative results (notice that greater scores on the SADI reflects greater SA impairments, while lower scores on our scale points lower AD level), so the *ad-hoc* scale allows us to assess SA accurately.

## **Chapter II. Objectives and hypothesis**

This entire research has the aim to address the concept of SA in patients with ABI, and go deeper into the importance of considering the relevance of implementing specific interventions in the context of the global rehabilitation process. Thus, three independent although related studies have been carried out, each of them with specific objectives and hypothesis.

### **1. First Study: “*La conciencia de déficit como proceso clave en la rehabilitación de los pacientes con daño cerebral adquirido: revisión sistemática*”.**

The general objective of this first experiment was to perform a systematic review of the literature focused on the role of SA in the rehabilitation of patients with ABI. Results from this systematic review would deliver a comprehensive overview of available evidence on the topic and allow to identify the most relevant research gaps in the field.

Before a first conceptualization of SA, the specific objectives of the systematic review were focused on evaluating the state of the literature in three relevant aspects of interest: the relationship between SA and cognitive functioning, specific intervention programmes for SA and the relationship between SA status and daily living functionality. We expected to find SA frequently related with cognitive performance, mainly executive functions, in the existent literature. We also expected to find considerable amount of studies that would have implemented specific SA interventions and measuring their effectiveness in terms of improvement in SA, with overall positive results. Contrary, we did not expect to find extensive research

relating improvements in SA and enhancements in functionality. Finally, we expected to find intervention programmes in SA poorly described in terms of procedures (sessions, activities performed, materials, etc.), which in turn would make difficult to extract conclusions.

**2. Second study: “*Efficacy of an intervention programme for rehabilitation of awareness of deficit after acquired brain injury: A pilot study*”**

The aim of the second study was to develop an intervention programme in SA for patients with ABI, as well as test its efficacy.

The literature reviewed had revealed that there were considerable intervention programmes that had been developed in order to increase SA of patients with ABI. Considering the most used techniques and procedures, and reflecting on the strengths and limitations of these programmes, the first specific objective of this study was to design and develop a specific intervention programme, including those techniques that had proved their efficacy. Consequently, the second objective was to implement this new intervention programme in a group of patients who were involved in a global rehabilitation process in the CEADAC. Finally, the third specific objective was to evaluate the efficacy of the intervention programme by comparing this group of patients with an equivalent one whose patients also received a global rehabilitation but with no a specific intervention in SA.

Importantly, a major aim of the work was to provide a neat description of the intervention programme, including how it was developed, the amount of sessions included, the concrete tools and material employed in each session, and the strategies implemented in the general process, among other

important details. This degree of detail was thought in order to avoid an important weakness of the literature in the field and allow clinicians and researchers to easily consider, evaluate and even implement this specific programme or potential adaptions based on it.

The main hypothesis of this study was related to the effectiveness of the proposed intervention programme proposed. In particular, and based on previous literature providing evidence of the usefulness techniques such as psychoeducation or feedback, we expected that patients who received the specific treatment would experience an increase of SA significantly higher than those in the control group.

### **3. Third study: “*Improving self-awareness after acquired brain injury leads to enhancements in patients’ daily living functionality*”**

The major objective of the third study was to explore the potential relationship between SA and daily living functionality of patients with ABI. Once we have studied the results of implementing an intervention programme on SA, we consider essential to explore whether the increase of SA would extend to patients’ functional outcome, enhancing their functionality in the activities of daily living.

The final goal of any rehabilitation programme with patients with ABI should be to make them as independent as possible in their daily activities. Previous literature had showed that intervening in SA could be an effective strategy to improve functionality and autonomy in these patients. In particular, it seems to improve the adjustment between reality and the patient's perception of their difficulties and limitations, which in turn allows

to set more realistic goals and benefits adherence and motivation towards treatment. Notwithstanding, research have provided mixed evidence in this regard (Engel et al., 2017), probably due to the variability in the approaches and scales used to assess functionality to the date.

Thus this third study aimed to explore the direct relationship between enhancements in SA, reached through the implementation of our intervention programme, and succeeding improvements of functionality in the instrumental activities of daily living (such as the ability to prepare food or to use mode transports). In this regard, we expected that those patients who achieved greater improvements in SA would be also the ones who reached greater daily living functionality at discharge.

**Chapter III. “La conciencia de déficit como proceso clave en la rehabilitación de los pacientes con daño cerebral adquirido: revisión sistemática”**

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## Resumen

*Introducción:* La afectación de la conciencia de déficit es un síntoma habitual de los pacientes que sufren una lesión cerebral, afectando al proceso rehabilitador y a los logros en términos de independencia funcional del paciente. *Pacientes y métodos:* Se realizó una revisión sistemática en las bases bibliográficas Scopus y Pubmed de aquéllos trabajos científicos que han abordado la conciencia de déficit en pacientes con daño cerebral entre los años 2000 y 2019. Finalmente se revisaron 65 artículos. *Resultados:* La conciencia de déficit como proceso metacognitivo, está ligada a otros procesos cognitivos de orden superior como las funciones ejecutivas y la memoria. En los últimos años, se han diseñado e implementado programas de intervención específicos sobre conciencia de déficit que han demostrado su eficacia mediante la incorporación de diferentes técnicas (i.e psicoeducación y feedback). Ante la necesidad de evaluar el éxito de la intervención sobre la conciencia de déficit en términos de mejora funcional, algunos trabajos han estudiado la generalización y trasferencia de los resultados de la intervención sobre la conciencia de déficit a las actividades de la vida diaria. *Conclusiones:* La investigación en conciencia de déficit en pacientes con daño cerebral se ha desarrollado de forma significativa en los últimos años, considerando los factores neuropsicológicos, psicológicos y sociales de este fenómeno. Su futuro prometedor apunta hacia su incorporación como screening en los protocolos de evaluación y, en su caso, su intervención de forma específica, contribuyendo a una rehabilitación eficaz que repercuta en la calidad de vida de los pacientes.

**Palabras clave:** Conciencia de déficit. Daño cerebral adquirido. Funcionalidad. Metacognición. Neuropsicología. Rehabilitación.

## **Introducción**

Los pacientes con daño cerebral adquirido (DCA) presentan habitualmente falta de conciencia de déficit (self-awareness), tanto si éste es producido por un accidente traumático (Prigatano, 2005a), como por un accidente cerebrovascular (Starkstein, Jorge, & Robinson, 2010). Estos pacientes no entienden las dificultades físicas, cognitivas, comportamentales y emocionales causadas por la lesión, y la discapacidad que éstas le provocan, no considerando las repercusiones que sus déficits tienen en su capacidad funcional en las actividades de la vida diaria (Cheng & Man, 2006).

La afectación de la conciencia de déficit tras un DCA parece estar relacionada con algunas variables clínicas, que resulta interesante conocer. La severidad de la lesión parece influir en la afectación de la conciencia de déficit, estando ésta más alterada en los pacientes con daños más severos (Dirette, Plaisier, & Jones, 2008; Prigatano, 2005b; Richardson, McKay, & Ponsford, 2015). Así mismo, el tiempo transcurrido desde la lesión (time post-injury) también parece ser un factor influyente, dado que la conciencia de déficit aumenta con el paso del tiempo (Hart, Seignourel, & Sherer, 2009). De esta manera aquellos pacientes con el daño más reciente, tienen más afectación de la conciencia (Richardson, McKay, & Ponsford, 2014), mientras que son los pacientes con más tiempo desde la lesión los que muestran una conciencia de los déficit, especialmente motores, más ajustada a la realidad (Richardson et al., 2015).

En pacientes con DCA, una adecuada conciencia de déficit está relacionada con la motivación hacia el proceso rehabilitador y con el éxito de éste (Ownsworth & Clare, 2006; Winkens, Van Heugten, Visser-Meilis, & Boosman, 2014), de manera que menores niveles de conciencia de déficit se asocian con un menor grado de independencia funcional (Hurst, Ownsworth,

Beadle, Shum, & Fleming, 2018). Sin embargo, una adecuada conciencia de déficit se asocia a una baja autoestima y un mayor nivel de depresión (Carroll & Coetzer, 2011), a un mayor nivel de estrés (Geytenbeek, Fleming, Doig, & Ownsworth, 2017) y a una menor percepción de calidad de vida (Sasse et al., 2013), si bien se ha sugerido que estas relaciones podrían desaparecer a largo plazo (Chesnel et al., 2018).

En este sentido, se ha planteado que un adecuado abordaje de los problemas en conciencia de déficit en pacientes con DCA debe considerar no sólo los aspectos neuropsicológicos, sino también los puramente psicológicos. Si bien las alteraciones cognitivas en estos pacientes juegan un papel fundamental en la presencia de una conciencia de déficit reducida, la lesión cerebral y la nueva situación que ésta comporta para el paciente probablemente desencadenan mecanismos psicológicos de negación, relacionados con la evitación de la angustia emocional que supone la nueva situación. De esta forma, el paciente conocería sus síntomas y déficits pero los ignoraría, con la finalidad principal de evitar la angustia que le provocan (Gasquoine, 2016). Por tanto, los problemas de conciencia de déficit en estos pacientes son probablemente consecuencia de la presencia de factores psicológicos y neuropsicológicos (Gasquoine, 2016; Ownsworth, McFarland, & Young, 2002). De acuerdo con este planteamiento, el modelo biopsicosocial de la conciencia (Biopsychosocial model of unawareness) (Ownsworth, Clare, & Morris, 2006), contempla diferentes factores asociados a la conciencia de déficit; los factores neuropsicológicos explican la ausencia de conciencia sobre la afectación de los diferentes dominios, interaccionando con factores psicológicos (entre los que destaca la negación) y factores sociales. Este modelo dinámico ha sido especialmente considerado de cara a diseñar programas de intervención sobre la conciencia de déficit (Fleming & Ownsworth, 2006).

Uno de los modelos explicativos de la conciencia de déficit en DCA más temprano es el propuesto por Crosson et al (Crosson et al., 1989) que presenta una perspectiva funcional y divide la conciencia de déficit en tres niveles jerárquicos. En la base de la pirámide del modelo se encuentra la “intellectual awareness” que hace referencia a la habilidad del paciente para reconocer sus déficits o funciones afectadas. En segundo lugar la “emergent awareness” describe la habilidad de percibir y describir las dificultades que el paciente presenta en el momento en que están ocurriendo, y en tercer lugar “anticipatory awareness”, hace referencia a la capacidad de predecir las dificultades que puede encontrar cuando se enfrente a una determinada situación (Crosson et al., 1989). Sin embargo, la estructura jerárquica de este modelo ha sido puesta en entredicho, y en un modelo posterior Toglia et al (Toglia & Kirk, 2000) remarcan la interacción entre dos componentes fundamentales de la conciencia de déficit: metacognitivo (“metacognitive knowledge”) que hace referencia al conocimiento sobre las propias habilidades (y que sería similar al intellectual awareness), y online (“online monitoring”), en relación a la conciencia del rendimiento in situ durante la realización de la tarea o actividad (y que englobaría la emergent y anticipatory awareness) (Toglia & Kirk, 2000). El conocimiento preciso de las capacidades personales antes de realizar una tarea sustenta otras habilidades metacognitivas, como la anticipación ante un reto, el uso planificado de estrategias compensatorias y la detección y comprobación de errores (Ownsworth, 2017).

Esta distinción se ha tomado en consideración en la investigación sobre conciencia de déficit en DCA, lo que ha dado lugar al desarrollo de instrumentos de evaluación y programas de intervención centrados específicamente en el aspecto online o en el aspecto metacognitivo de la conciencia. En esta revisión nos centraremos fundamentalmente en el segundo de ellos, analizando aquellos estudios que han abordado la

conciencia de déficit como un proceso metacognitivo, entendiendo la metacognición como una función cognitiva de orden superior relacionada con el conocimiento y las creencias sobre las habilidades cognitivas de uno mismo (Kennedy et al., 2008; Stuss & Anderson, 2004). Desde esta perspectiva, considerar la relación entre la conciencia de déficit y otros procesos cognitivos resulta particularmente relevante. Recientes estudios han mostrado la relación y el papel contributivo de diferentes procesos cognitivos, como la memoria y las funciones ejecutivas, en la conciencia de déficit de los pacientes con DCA (Belchev et al., 2017; Long, Rager, & Adams, 2014; Morton & Barker, 2010; Zimmermann, Mograbi, Hermes-Pereira, Fonseca, & Prigatano, 2017).

Así mismo, conocida la repercusión que tiene una adecuada conciencia de déficit en el proceso rehabilitador y la mejora de los pacientes con DCA (Ownsworth & Clare, 2006), son numerosas las investigaciones que se han realizado con el fin de diseñar e implementar programas de intervención que permitan aumentar la conciencia de déficit en estos pacientes. Mediante el uso de diferentes técnicas de intervención (e.g. práctica de tareas con auto predicción de resultados anticipados, feedback externo de compañeros y profesionales, roleplaying, psicoeducación, etc. (Schrijnemaekers, Smeets, Ponds, van Heugten, & Rasquin, 2014)), la mayor parte de estos programas han obtenido resultados favorables consiguiendo mejorar la conciencia de déficit (Engel, Chui, Goverover, & Dawson, 2017).

No obstante, el objetivo fundamental de los programas de rehabilitación en DCA es permitir la generalización y trasferencia de sus resultados a las actividades funcionales de la vida diaria de los pacientes. Si bien son pocos los estudios que han analizado los beneficios funcionales de la intervención específica en conciencia de déficit, los resultados sugieren que los incrementos en conciencia pueden transferirse al estado funcional

de los pacientes y a su grado de independencia en las actividades de la vida diaria (Engel et al., 2017; Villalobos, Bilbao, López-Muñoz, & Pacios, 2019).

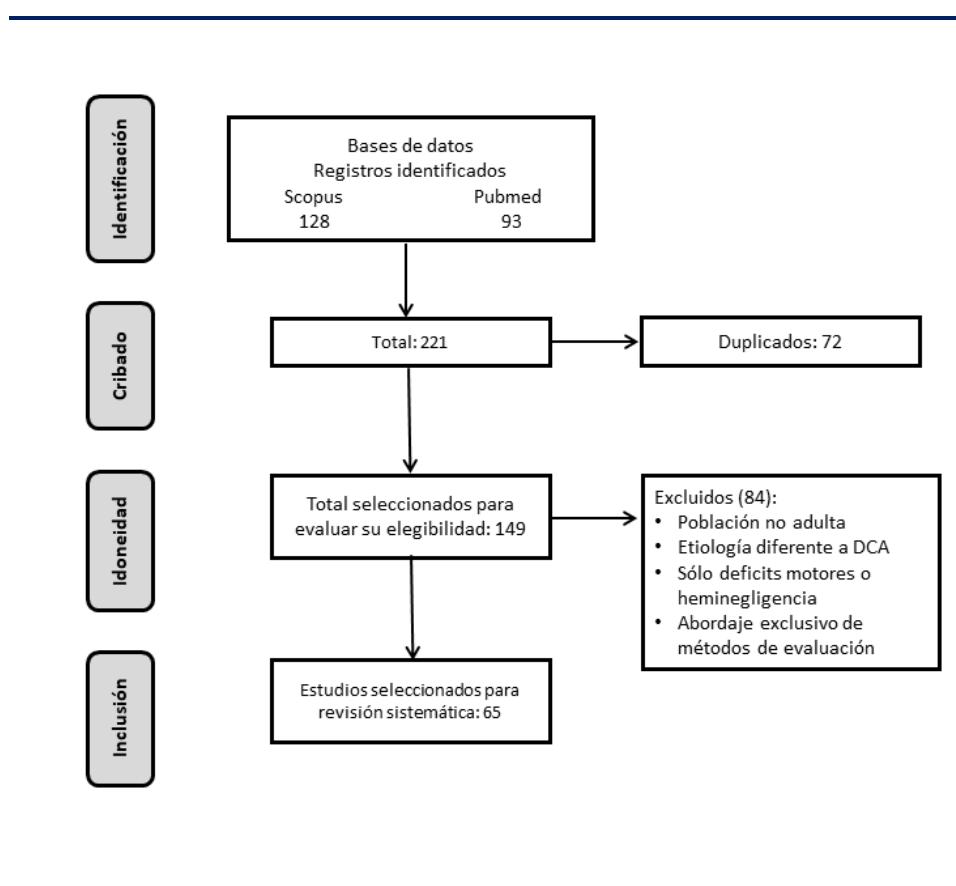
El objetivo de esta revisión es ofrecer una visión global e integradora sobre la conciencia de déficit en pacientes con DCA, analizar su relación funcional con otros procesos cognitivos y la importancia de intervenir sobre ella en el contexto de la rehabilitación global, dada su influencia en el grado de independencia alcanzado por el paciente.

## **Pacientes y Métodos**

Para este trabajo se ha llevado a cabo una revisión sistemática siguiendo las directrices PRISMA (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009). La estrategia de búsqueda bibliográfica utilizada en las bases Scopus y Pubmed fue: “self-awareness” OR “awareness of deficit” OR “anosognosia” AND “brain injury” OR “brain damage” OR “traumatic brain injury” OR “stroke”. Se consideraron los artículos publicados entre el año 2000 y el 2019, en lengua inglesa y con pacientes humanos. La búsqueda inicial generó 128 resultados en Scopus y 93 en Pubmed. A continuación se eliminaron los duplicados ( $n=72$ ) y se analizaron los títulos y abstracts de los artículos restantes ( $n=149$ ) para garantizar la inclusión única de aquéllos que cumplieran los siguientes criterios:

- Incluir únicamente población adulta.
- Considerar únicamente DCA, sin tener en cuenta otras etiologías.
- Abordar la conciencia de déficit a nivel cognitivo, no sólo como parte de un cuadro de heminegligencia o a nivel exclusivamente motor, o no sólo como parte del desarrollo, baremación o validación de un instrumento de medida.

Como resultado de la aplicación de dichos criterios, la muestra final de artículos considerados fue de 65 (Figura 4), sobre los cuales se realizó una tabulación descriptiva. Cada uno de los estudios fue clasificado en función de los temas de interés principal a abordar en la revisión: conceptualización de la conciencia de déficit, relación entre conciencia de déficit y funcionamiento cognitivo, programas de intervención sobre la conciencia de déficit. Dentro de cada uno de estos aspectos, se consideraron también si los artículos evaluaron o no los resultados en términos de funcionalidad del paciente.



**Figura 1:** Proceso de selección de los artículos incluidos en la revisión sistemática.

## **Resultados**

### **Conciencia de déficit y funcionamiento cognitivo**

Considerar la conciencia de déficit como un proceso metacognitivo requiere necesariamente conocer cómo ésta se relaciona con otros procesos cognitivos de orden superior, particularmente las funciones ejecutivas. Las funciones ejecutivas son una serie de procesos cognitivos integrados que nos permiten formular metas, iniciar comportamientos y anticipar las consecuencias de la acción, planificar y organizar dicho comportamiento supervisándolo y adaptándolo a la tarea o contexto particular (Cicerone et al., 2000). Si bien parece razonable que un adecuado y ajustado conocimiento del funcionamiento de nuestros procesos cognitivos se relacione con nuestra capacidad para planificar y supervisar nuestras conductas de forma adecuada, la dirección de esta relación es objeto de debate. El correcto funcionamiento de las funciones ejecutivas puede entenderse como un elemento necesario para que el paciente con DCA sea consciente de los déficits que la lesión le ha provocado, así como de la discapacidad asociada (Bivona et al., 2008; Bogod, Mateer, & MacDonald, 2003). Sin embargo, un adecuado conocimiento sobre el propio rendimiento cognitivo parece necesario para poder llevar a cabo el conjunto de conductas que nos permiten ajustar y supervisar nuestro comportamiento a los objetivos deseados (Tate et al., 2014).

De entre los estudios que han explorado las relaciones entre conciencia de déficit y otros procesos cognitivos, algunos han mostrado relaciones directas entre la conciencia de déficit y medidas de función ejecutiva, tanto general (Hart, Whyte, Kim, & Vaccaro, 2005), como en procesos específicos de flexibilidad cognitiva (Ciurli et al., 2010) e inhibición

(Bogod et al., 2003). Además, se ha sugerido que esta relación estaría también presente en medidas de memoria (Long et al., 2014).

Más interesante, estudios empleando análisis de regresión han mostrado el valor predictor de algunas funciones cognitivas en la conciencia de déficit, aunque otras investigaciones no han encontrado esta relación (Belchev et al., 2017). De nuevo, el rendimiento en función ejecutiva, particularmente en procesos de monitorización y flexibilidad cognitiva (Morton & Barker, 2010; Noé et al., 2005; Zimmermann et al., 2017), inhibición (Bogod et al., 2003) y categorización (Goverover, 2004) parece ser un buen predictor del nivel de conciencia de déficit. Además, se ha sugerido que el rendimiento en memoria podría predecir también el nivel de conciencia de déficit en pacientes con DCA (Noé et al., 2005; Zimmermann et al., 2017).

Dado el rol que algunas funciones cognitivas, particularmente las funciones ejecutiva y la memoria, parecen tener en el nivel de conciencia de déficit de los pacientes con DCA, resulta interesante conocer si el rendimiento de los pacientes en dichas funciones puede a su vez predecir el grado de mejoría en conciencia de déficit durante el proceso de rehabilitación. De ser así, esta información sería relevante para el diseño y desarrollo de programas de intervención en conciencia de déficit, en tanto que se esperaría que incidir en la rehabilitación de dichas funciones cognitivas tendría un impacto beneficioso en la rehabilitación de la conciencia de déficit en sí misma.

### **Programas de intervención en conciencia de déficit**

Tras sufrir una lesión cerebral, el sistema cognitivo tiene la potencialidad de experimentar una mejoría espontánea en muchas de sus funciones, particularmente en conciencia de déficit (Hart et al., 2009;

Richardson et al., 2014). A pesar de ello, implementar programas específicos de rehabilitación de esta habilidad puede contribuir a acelerar e incrementar el grado de mejoría experimentado, incidiendo a su vez en la eficacia del proceso rehabilitador global (Leung & Liu, 2011).

Muchos de los programas de intervención desarrollados hasta la fecha se basan en conseguir que el paciente conozca su lesión, acepte sus déficits o problemas causados por ella y conozca las implicaciones que su situación actual implica para sus actividades de la vida diaria, consiguiendo de esta manera que plantea objetivos ajustados a la realidad. Si bien este aumento en la conciencia de déficit puede resultar en una mayor funcionalidad del paciente (Villalobos et al., 2019), el mayor nivel de conciencia de la propia discapacidad se ha asociado también a mayores niveles de ansiedad (Fleming, Lucas, & Lightbody, 2006). De esta manera, establecer una buena alianza terapéutica, aspecto fundamental en cualquier proceso de rehabilitación de pacientes con DCA, es especialmente relevante en aquellos casos en los que se encuentra alterada la conciencia de déficit y ésta va a ser objeto de intervención (Ownsworth, 2017).

En una revisión temprana sobre programas de intervención en conciencia de déficit en DCA, Lucas et al (Lucas & Fleming, 2005) identificaron por primera vez las estrategias de intervención más frecuentemente utilizadas: la psicoeducación, diferentes tipos de feedback, la comparación de la autoevaluación con el desempeño real en la tarea, la terapia conductual y la psicoterapia (Lucas & Fleming, 2005) (Ver Tabla 1 para una descripción de las estrategias).

En una revisión posterior realizada por Fleming et al (Fleming & Ownsworth, 2006), basándose en una aproximación biopsicosocial de las alteraciones en conciencia de déficit (Ownsworth et al., 2006), las autoras propusieron la importancia de distinguir entre factores neuropsicológicos,

psicológicos y socioculturales para la selección de herramientas y estrategias de rehabilitación más adecuadas a cada caso (ver Tabla 1). Por ejemplo, el uso del feedback y la realización de tareas realistas y estructuradas, en las que el paciente pueda evaluar su desempeño, descubrir sus errores y compensar los déficits, resultaría particularmente efectiva en aquellos pacientes con problemas ejecutivos que estén influyendo en la falta de conciencia de déficit. Por el contrario, aquéllos que son capaces de reconocer sus déficits pero los niegan, debido a mecanismos psicológicos y emocionales subyacentes, podrían beneficiarse en mayor medida de una aproximación basada en una buena alianza terapéutica y en el uso de la psicoeducación, la psicoterapia y la promoción y reforzamiento de la aceptación del cambio (Fleming & Ownsworth, 2006).

Posteriormente Leung et al (Leung & Liu, 2011) realizaron una revisión sobre la conciencia de déficit en pacientes que habían sufrido un accidente cerebrovascular. En ella revisaron el concepto de conciencia de déficit, los principales instrumentos de medida y los programas de intervención desarrollados hasta la fecha, subrayando el hecho de que la mayor parte de estos utilizan estrategias que pueden ser consideradas restaurativas (en contraposición a las estrategias compensatorias). Particularmente interesante es la descripción de los autores del abordaje de la conciencia de déficit a través de un programa de rehabilitación específico de pacientes con ictus (en el marco de la “constraint induces movement therapy” CMT) (Leung & Liu, 2011).

Finalmente, en una reciente revisión sistemática llevada a cabo por Schrijnemakers y cols., (2014), los autores mostraron que, en general, implementar un programa de intervención específica sobre la conciencia de déficit, en el contexto del proceso global de rehabilitación, aumenta el nivel de conciencia de los pacientes en el momento del alta. Los resultados de su

revisión mostraron también que con frecuencia los diferentes programas incluyen una combinación de varias técnicas de intervención, siendo las más comunes la psicoeducación y el feedback, señalando a su vez la necesidad de desarrollar estudios que permitan identificar las técnicas más beneficiosas (Schrijnemakers et al., 2014). Con dicha finalidad, Kersey et al (Kersey, Juengst, & Skidmore, 2019) estudiaron la eficacia de diferentes estrategias de intervención sobre la conciencia de déficit, vinculadas al tipo de enfoque durante la realización de tareas estructuradas. Compararon la “metacognitive training strategy”, en la que el paciente guía su autoevaluación y desarrollo de soluciones propias para las dificultades encontradas en la tarea, con el “direct skill training” en el que es el terapeuta quién proporciona las instrucciones específicas para completar la tarea, eliminando el componente de autoevaluación y limitando la oportunidad del aprendizaje por error. Hallaron que ambas estrategias aumentaban por igual la conciencia de déficit, especialmente el componente relacionado con el diseño e implementación de estrategias compensatorias (Kersey et al., 2019).

	<b>Descripción</b>	<b>Aspectos a destacar</b>	<b>Uso apropiado en función del componente alterado</b> (Toglia & Kirk, 2000)	<b>Uso apropiado en función de los factores en la base de la afectación</b> (Fleming & Ownsworth, 2006)
<b>Psicoeducación</b>	Formación sencilla sobre la naturaleza de la lesión, los déficits asociados, y las	Se pueden emplear técnicas de neuroimagen e informes técnicos.	Metacognitivo	Factores Neuro-cognitivos Factores Sociales

	implicaciones funcionales de dichos déficits.	(e.g. neuropsicológicos)		
<b>Feedback</b>	Comentarios constructivos sobre el desempeño del paciente en una tarea. Ésta debe ser específica, oportuna, consistente y respetuosa.	Existen diferentes modalidades en función de la persona que lo suministre (terapeuta, compañeros, etc.) y si es directo o mediante grabación.	Online	Factores Neuro-cognitivos
<b>Realización de tareas estructuradas</b>	Involucrar al paciente en experiencias estructuradas que permitan el autocontrol y la autoevaluación. A medida que va ejerciendo control y ganando dominio sobre la tarea, su autoeficacia y conocimiento metacognitivo se reestructura y fortalece.	El paciente realiza una previsión de su desempeño en la tarea y después de su realización puntúa su propio rendimiento.	Online	Factores Neuro-cognitivos
<b>Terapia conductual</b>	Entrenamiento en estrategias compensatorias basadas en el aprendizaje implícito y la formación de hábitos.	Recomendado o cuando las estrategias de confrontación pueden causar agitación y afianzar creencias confabulatorias.	Metacognitivo	Factores Psicológicos

Psicoterapia	Ayuda a los pacientes a restablecer un sentido al significado de sus vidas y formar metas realistas.	Formado por diferentes técnicas específicas que puede incluir, por ejemplo, la realización de listas de fortalezas y debilidades.	Metacognitivo	Factores Psicológicos Factores Neurocognitivos Factores Sociales
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**Tabla 1.** Principales herramientas y técnicas de intervención sobre conciencia de déficit en daño cerebral adquirido

A la luz de la literatura revisada, las técnicas de feedback al paciente parecen ser las más comúnmente utilizadas en la intervención en conciencia de déficit en pacientes con DCA. La estrategia concreta varía desde la administración verbal por parte del terapeuta, que describe los aspectos positivos y negativos del rendimiento del paciente en una tarea, el empleo de grabaciones de video sobre la ejecución del propio paciente, hasta el formato de intervención grupal en el que el resto de pacientes implicados también colaboran en la provisión de feedback. En una revisión sistemática, Schmidt et al (Schmidt, Lannin, Fleming, & Ownsworth, 2011) concluyeron que el uso de feedback dentro de un programa de intervención induce una mejoría significativa de tamaño moderado en la conciencia de déficit de los pacientes con DCA (Schmidt et al., 2011). En un trabajo posterior del mismo grupo, el feedback a través de grabaciones de video mostró ser efectivo en un grupo de pacientes con DCA, en un ensayo controlado aleatorizado (Schmidt, Fleming, Ownsworth, & Lannin, 2015). Así mismo, Tate et al (Tate et al., 2014), en unas guías con recomendaciones para el manejo de los problemas ejecutivos y la conciencia de déficit tras un DCA, señalaba el feedback como una herramienta especialmente relevante para aumentar la conciencia de déficit (Tate et al., 2014).

Trabajos más recientes han mostrado que implementar un programa de intervención en conciencia de déficit, en el contexto del proceso global de rehabilitación, tiene efectos beneficiosos en el nivel de conciencia de los pacientes en el momento del alta, en comparación con pacientes que únicamente reciben un programa de rehabilitación global, más aún, parece que los pacientes con bajo nivel de conciencia al inicio de la rehabilitación, son aquéllos que más se benefician de la intervención específica en conciencia de déficit (Villalobos, Bilbao, Espejo, & García-Pacios, 2018). Incluso se ha sugerido que dichos programas, además de mejorar la conciencia de déficit, pueden tener un impacto positivo en la mejora de las habilidades sociales de los pacientes (Llorens, Noé, Ferri, & Alcañiz, 2015).

### **Conciencia de déficit y funcionalidad**

En general los resultados de diferentes investigaciones parecen mostrar que el nivel de conciencia de déficit se asocia a la recuperación funcional de los pacientes con DCA (Ownsworth & Clare, 2006). Los estudios con resultados positivos han encontrado que el grado de conciencia en el momento del alta parece relacionarse con el número de actividades en las que el paciente se encuentra involucrado en comparación con su situación anterior a la lesión (Hartman-Maeir, Soroker, Oman, & Katz, 2003), con el nivel de independencia funcional en actividades del dia a día (Fischer, Gauggel, & Trexler, 2004), y con el grado de empleabilidad del paciente al alta del proceso rehabilitador (Sherer et al., 2003), incluso cinco años o más después de haber sufrido la lesión cerebral (Kelley et al., 2014).

De esta manera, intervenir sobre la conciencia de déficit dentro del proceso rehabilitador resulta fundamental, en tanto que el objetivo prioritario de éste es incrementar la funcionalidad e independencia del

paciente. Como hemos revisado previamente, son numerosos los programas de intervención diseñados para tal fin; sin embargo, estos no siempre evalúan el resultado de su implementación en términos de mejoras funcionales logradas (generalización y transferencia a actividades de la vida diaria).

Con el fin de revisar los programas de intervención sobre conciencia de déficit en DCA, conocer las herramientas empleadas y analizar sistemáticamente los diferentes resultados reportados de dichas intervenciones, Engel et al (Engel et al., 2017) realizaron una valiosa revisión sistemática. Los autores actualizaron la selección de trabajos reportada en revisiones previas (Fleming & Ownsworth, 2006; Leung & Liu, 2011; Lucas & Fleming, 2005; Schmidt et al., 2011; Schrijnemaekers et al., 2014), añadiendo estudios de reciente publicación y eliminando aquéllos en los que no se informaba exhaustivamente de resultados de la intervención, se aportaba información exclusivamente cualitativa, o se incluían pacientes sin afectación de la conciencia de déficit. El análisis de la literatura mostró que los pacientes que realizan un programa específico de intervención en conciencia de déficit mejoran en actividades no entrenadas pero parecidas a las presentes en la intervención (transferencia cercana), así como en otras diferentes y no relacionadas, lo que sugiere que los beneficios inducidos por ésta pueden transferirse parcialmente (Braden et al., 2010; Cheng & Man, 2006; Goverover, Johnston, Toglia, & Deluca, 2007; Landa-González, 2001; Noé et al., 2005; Ownsworth, Quinn, Fleming, Kendall, & Shum, 2010; Tham, Ginsburg, Fisher, & Tegnér, 2001; Toglia, Goverover, Johnston, & Dain, 2011; Toglia, Johnston, Goverover, & Dain, 2010). Sin embargo, no todos estos estudios implementaban programas de intervención específicos sobre la conciencia de déficit o no evaluaban de forma específica la generalización de los resultados al entorno real del paciente tras la rehabilitación, aspecto que en última instancia resulta especialmente interesante analizar.

Los resultados de esta revisión sistemática muestran que hasta la fecha, once estudios han explorado la capacidad de un programa de intervención específico en conciencia de déficit para inducir una mejoría, no sólo en conciencia de déficit sino también en funcionalidad en actividades de la vida diaria, en pacientes con DCA (ver Tabla 2). La suma total de pacientes considerados en todos ellos asciende a un total de 434. De estos estudios, siete encontraron correlaciones significativas entre la mejora en conciencia de déficit lograda con el programa de intervención administrado, y unos mejores resultados funcionales en las actividades de la vida diaria (Goverover et al., 2007; Malec & Moessner, 2000; Ownsworth & McFarland, 2004; Ownsworth, McFarland, & Young, 2000; Skidmore, Swafford, Juengst, & Terhorst, 2018; Tham et al., 2001; Villalobos et al., 2019). Así mismo, comparando pacientes con y sin alteraciones en conciencia de déficit, Noé y cols en 2005 observaron que tras implementar un programa de rehabilitación integral en pacientes con DCA, con una sección específica dedicada a la intervención en conciencia de déficit, los pacientes con mayores alteraciones iniciales en conciencia de déficit eran los que experimentaban una mayor mejoría en el grado de independencia funcional en las actividades básicas, aunque no en las actividades instrumentales de la vida diaria (Noé et al., 2005)].

No obstante, algunos estudios que han implementado un programa de intervención sobre la conciencia de déficit no han encontrado que el aumento de ésta se asocie a una mejora funcional en las actividades instrumentales de la vida diaria (Cheng & Man, 2006; Schmidt, Fleming, Ownsworth, Lannin, & Khan, 2012), si bien no todos ellos se centraron en el componente metacognitivo de la conciencia de déficit (Schmidt et al., 2012).

Por último, resulta interesante mencionar el estudio de Smeets el al (Smeets, Vink, Ponds, Winkens, & van Heugten, 2015), en el que

distinguieron entre pacientes que subestiman sus competencias, maximizando sus déficits, y aquellos que, al contrario, sobrevaloran sus competencias y minimizan e infravaloran sus déficits. Sus resultados mostraron que son los primeros los que, a través de un programa específico de intervención, consiguen ajustar a la realidad su conciencia, así como aumentar algunos aspectos relacionados con la autonomía en las actividades de la vida diaria o las relaciones sociales. Por contra, los pacientes que infravaloraban sus déficits no obtuvieron una mejora funcional después de la intervención (Smeets et al., 2015).

A pesar de la variabilidad metodológica entre los estudios publicados hasta la fecha (i.g. diferentes etiologías en las muestras de pacientes estudiados, diferencias en los procedimientos de intervención y en los instrumentos de medida de conciencia de déficit y funcionalidad, etc.), el conjunto de investigaciones revisadas muestra que intervenir específicamente sobre la conciencia de déficit es una estrategia eficaz para mejorar la funcionalidad y autonomía del paciente con DCA. Específicamente, la rehabilitación del nivel de conciencia de déficit parece mejorar el ajuste de la percepción del paciente sobre sus dificultades y limitaciones con la realidad, permitiendo el establecimiento de objetivos realistas y fomentando una mayor adherencia y motivación hacia el tratamiento. De este modo, el proceso global de rehabilitación incrementa su eficacia, lo que en última instancia se asocia a una mejora funcional en las actividades de la vida diaria.

Tamaño de la muestra (G.Exp/ G.Control) y etiología de la lesión	Estrategias del programa de intervención sobre conciencia de déficit	Instrumentos evaluación de conciencia de déficit	Instrumentos de evaluación de la funcionalidad	Resultados:
(Cheng & Man, 2006)	21 (11/10) Traumático cráneo encefálico (TCE)	- Ejecución tareas reales - Educación - Feedback externo	- SADI  - FIM - Lawton IADL	Mejora en conciencia de déficit.  No mejora funcional
(Goverover, Johnston, Toglia, & Deluca, 2007)	20 (10/10) Daño cerebral adquirido (DCA)	- Ejecución tareas reales - Educación - Feedback externo	- AAD - AQ - SRSI	Mejora en conciencia de déficit durante la tarea.  Mejora funcional
(Malec & Moessner, 2000)	62 (62/0) DCA	- Psicoeducación - Role-playing - Psicoterapia	- MPAI  - ILS - VIS	Mejora en conciencia de déficit  Mayor independencia funcional [no empleabilidad]
(Noé et al., 2005)	62 (62/0) DCA  *2 grupos en función del grado de conciencia	- Ejecución tareas reales - Educación - Psicoterapia	- PCRS  - DRS - BI-m - FIM-FAM	Mejora funcional (solo en BI-m)  No evalúa mejora en conciencia
(Ownsworth, McFarland, & Young, 2000)	21 (21/0) DCA	- Ejecución tareas reales - Educación - Feedback externo	- SADI - HIBS - SRSI	Mejora en conciencia de déficit (self-regulation)  Mejora funcional
(Ownsworth & McFarland, 2004)	26 (26/0) DCA	- Ejecución tareas reales - Educación - Feedback externo	- SRSI  - SIP - ILS - TTT	Correlación positiva entre mejora en conciencia y mejora funcional (psicosocial)

(Schmidt et al., 2012)	54 (54/0) TCE *3 grupos en función del feedback en la intervención	- Ejecución tareas reales - Feedback externo directo y vídeo	- AQ	- SPIRQ	Mejora en conciencia de déficit (online); más evidente en el grupo que usa videofeedback No correlación con mejora funcional.
(Skidmore, Swafford, Juengst, & Terhorst, 2018)	30 (15/15) Accidente cerebro vascular	- Ejecución tareas reales - Feedback externo	- SADI	- FIM	Mejora funcional
(Smeets, Vink, Ponds, Winkens, & van Heugten, 2015)	78 (78/0) DCA *3 grupos en función del grado de conciencia	- Ejecución tareas reales - Educación - Feedback externo	- PCRS	- QOLIBRI	Mejora en conciencia de déficit y mejora funcional en aquellos que inicialmente sobreestimaban sus déficits/infraestimaban sus competencias
(Tham, Ginsburg, Fisher, & Tegnér, 2001)	4 [4/0] Accidente cerebro vascular	- Ejecución tareas reales - Feedback externo - Psicoterapia	- AAD	- AMPS	Mejora en conciencia de déficit (discapacidad) Mejora funcional
(Villalobos et al., 2019)	56 (28/28) DCA	-Pico-educación - Feedback externo	- ECD	- Lawton IADL	Mejoran en conciencia de déficit Mejora funcional

SADI: Awareness of Deficits Interview; ADD: Assessment of awareness of disability; AQ: Awareness Questionnaire; SRSI: Self-Regulation Skills Interview; MPAI: Mayo-Portland Adaptability Inventory; PCRS: Patient Competency Rating Scale; HIBS: Head-Injury -Behaviour Scale; ECD: Escala de Conciencia de Déficit. AMPS: Assessment of Motor and Process Skills; BI-m: Barthel Index-modified; DRS: Disability Rating Scale; FIM: Functional Independence Measure; ILS: Independent Living Scale; Lawton IADL: Lawton Instrumental Activities of Daily Living Score; QOLIBRI: The Quality of Life in Brain Injury; SPIRQ: Self-perceptions in Rehabilitation Questionnaire; SIP: Sickness Impact Profile; TTT: The Tinkertoy Test; VIS: Vocational Independence Scale.

**Tabla 2.** Estudios que han evaluado la mejora funcional tras implementar un programa de intervención en conciencia de déficit, en pacientes con daño cerebral adquirido

## **Discusión**

La presente revisión pretende ofrecer un análisis global de las alteraciones en conciencia de déficit en pacientes con DCA, particularmente, de su relación con otras funciones cognitivas (i.e. funciones ejecutivas y memoria). Además, se revisa la literatura existente hasta la fecha sobre programas de intervención específicos en conciencia de déficit, su eficacia y su capacidad de influir en última instancia sobre la funcionalidad e independencia en las actividades de la vida diaria.

Aunque las alteraciones en conciencia de déficit tras un DCA tradicionalmente se han considerado desde un punto de vista fundamentalmente neuropsicológico, propuestas recientes subrayan la importancia de otros factores puramente psicológicos en el desarrollo de estas alteraciones (Gasquoine, 2016). En este sentido, se ha propuesto que los pacientes con DCA, en parte, recurren a estrategias de evitación de la angustia emocional que el conocimiento de su nueva situación les produce, con la finalidad de reducir el estrés que esta información les provoca. No obstante, la aproximación más frecuente en la actualidad considera tanto los factores psicológicos como los neuropsicológicos que subyacen a la afectación de la conciencia de déficit (Ownsworth et al., 2006). La lesión en sí misma afecta a la capacidad de autoreflexión y autocontrol, mientras que la forma en la que las personas dan sentido a la lesión cerebral y se presentan a los demás, depende de su personalidad, su estilo de afrontamiento y su entorno social (Ownsworth, 2017). Los pacientes con DCA comienzan a ser conscientes de sus déficits a partir de las reacciones de otras personas ante

sus fallos y errores en situaciones de la vida real. Este descubrimiento suele acompañarse de sentimientos de sorpresa y angustia que sin embargo, pueden paulatinamente disminuir si el paciente recibe una intervención y feedback adecuados. Durante este proceso el paciente puede sentir miedo y recurrir a la negación, de manera que la rehabilitación se convierte en un elemento fundamental, no sólo en la recuperación física y cognitiva, sino como un entorno que proporciona apoyo, respeto e información durante el proceso de reconocimiento de los déficits y las limitaciones causadas por la lesión (O'Callaghan, Powell, & Oyebode, 2006).

La relación entre las distintas capacidades cognitivas y las alteraciones en conciencia de déficit asociadas al DCA ha sido también objeto de investigación en la última década. Varios estudios han mostrado relaciones positivas entre la afectación de la memoria y la conciencia de déficit (Long et al., 2014), y especialmente con medidas de función ejecutiva (Bogod et al., 2003; Ciurli et al., 2010; Hart et al., 2005). Más interesante aún, algunas investigaciones han mostrado el valor predictor de procesos de memoria y función ejecutiva en la afectación de la conciencia de déficit tras un DCA (Bogod et al., 2003; Goverover, 2004; Morton & Barker, 2010; Noé et al., 2005; Zimmermann et al., 2017). Conocer la influencia que determinados procesos cognitivos ejercen en la afectación de la conciencia de déficit en estos pacientes resulta especialmente relevante para el abordaje de este proceso desde un punto de vista metacognitivo. Incidir en la rehabilitación de estos componentes cognitivos no sólo mejoraría el rendimiento cognitivo global del paciente sino que aumentaría la eficacia de los programas específicos de conciencia de déficit, incrementando su nivel de autoconocimiento y motivación hacia el proceso rehabilitador en conjunto.

De esta manera, incluir programas que intervengan de forma específica sobre la conciencia de déficit dentro del proceso rehabilitador de

pacientes con DCA, es un abordaje eficaz para aumentar la conciencia de los pacientes. Entre las diferentes técnicas empleadas en estos programas, las más frecuentemente utilizadas son la psicoeducación, la realización de tareas estructuradas en entornos reales, el feedback (en diferentes modalidades), la psicoterapia y la terapia conductual (Lucas & Fleming, 2005) (ver Tabla 2), aunque existen otras técnicas que pueden complementar la intervención (Fleming & Ownsworth, 2006). A la hora de identificar cuáles de estas herramientas conviene emplear en el abordaje de la conciencia de déficit, resulta especialmente interesante caracterizar los diferentes factores (neuropsicológicos, psicológicos y sociales) que contribuyen al reducido nivel de conciencia de déficit de cada paciente. De acuerdo con la literatura revisada hasta el momento, el profesional puede inferir la contribución relativa de los diferentes factores a partir de elementos clínicos como la ubicación de la lesión cerebral y los resultados de la evaluación neuropsicológica, pero también en base a la reacción del paciente ante el feedback o las dificultades que experimenta durante las tareas de rehabilitación, la información adicional de otras personas significativas, los distintos estilos de personalidad y afrontamiento, así como el análisis del entorno social y cultural del paciente (Fleming & Ownsworth, 2006). Una adecuada caracterización de la contribución de los factores neuropsicológicos, psicológicos y sociales permitirá al clínico diseñar un programa de intervención más eficaz para cada paciente con afectación de conciencia de déficit.

En general, la evidencia muestra que implementar programas de intervención en conciencia de déficit resulta beneficioso en pacientes con DCA (Schrijnemakers et al., 2014), particularmente en aquellos con peores niveles de conciencia en el momento del ingreso (Villalobos et al., 2018). Así mismo, a pesar de que una ajustada conciencia de déficit se asocia a la aparición de sintomatología depresiva (Goverover & Chiaravalloti, 2014), el

aumento de la conciencia de déficit inducido por un programa de intervención sobre la misma no necesariamente se asocia a un empeoramiento en el estado emocional (Schmidt, Fleming, Ownsworth, & Lannin, 2013), de manera que los beneficios asociados al desarrollo de una ajustada conciencia de déficit, parecen superar los potenciales efectos sobre el estado anímico del paciente.

En particular, la revisión de los estudios publicados hasta la fecha muestra que la rehabilitación de la conciencia de déficit no sólo mejor la capacidad del paciente para estimar apropiadamente sus capacidades y ajustar sus metas y objetivos de forma más realista, sino que este ajuste tiene un efecto beneficioso en la funcionalidad del paciente tras la rehabilitación. La mayor parte de los estudios sugieren que la mejora en conciencia de déficit puede transferirse y generalizarse a las actividades de la vida diaria del paciente con DCA, de manera que los pacientes que experimentan una mejoría más evidente en su conciencia de déficit, son también los que alcanzan una mayor independencia funcional tras la rehabilitación (Engel et al., 2017). Si bien la funcionalidad del paciente ha sido evaluada en entornos experimentales o empleando actividades similares a las entrenadas en el proceso rehabilitador (lo que dificulta extraer conclusiones precisas acerca del grado de transferencia y generalización al entorno real del paciente con DCA), existen estudios que evalúan la independencia funcional del paciente en su entorno real, y que sugieren que la mejora en conciencia efectivamente incrementa la funcionalidad tras la rehabilitación (Goverover et al., 2007; Malec & Moessner, 2000; Ownsworth & McFarland, 2004; Ownsworth et al., 2002; Skidmore et al., 2018; Tham et al., 2001; Villalobos et al., 2019).

Los actuales avances en el campo están facilitando el desarrollo de un nuevo escenario en el abordaje del paciente con DCA en los próximos años.

La adecuada caracterización de la conciencia de déficit podría derivar en el desarrollo de herramientas de screening de esta capacidad, similares a otras herramientas de screening cognitivo, ampliamente aceptadas en el campo, como el MMSE (Folstein, Folstein, & McHugh., 1975) o el MoCA (Cummings et al., 2005). Implementar estas pruebas de screening en los protocolos de evaluación inicial del DCA no requerirá excesivos recursos, ya que para la correcta evaluación de la conciencia de déficit no son necesarios amplios protocolos neuropsicológicos ni el empleo de técnicas de imagen, sólo la participación de personal clínico bien formado. Sin embargo, identificar tempranamente alteraciones en conciencia de déficit, en combinación con el desarrollo de nuevos protocolos de intervención (basados en las metodologías más recientes arriba mencionadas), facilitará un abordaje a medida de las necesidades de cada paciente. Estas intervenciones podrían incluso incorporar nuevas tecnologías como la realidad virtual, que han demostrado ser eficaces en el tratamiento de otras alteraciones cognitivas en pacientes con DCA (Alashram, Annino, Padua, Romagnoli, & Mercuri, 2019), como los déficit atencionales (Larson et al., 2011) y la heminegligencia (Ogourtsova, Souza Silva, Archambault, & Lamontagne, 2017).

El desarrollo actual de la disciplina y las líneas de investigación en desarrollo sugieren un futuro prometedor en la investigación aplicada y en la transferencia de sus resultados a la realidad clínica. La incorporación sistemática de la evaluación, y en su caso la intervención, en conciencia de déficit en los protocolos de rehabilitación del DCA supondrá una mejora sustancial en la atención global al paciente y sus familias. Más aún, estos protocolos podrían adaptarse al trabajo con otras poblaciones clínicas también afectadas en conciencia de déficit, como algunos tipos de demencia, trastornos mentales e incluso en adicciones (Le Berre & Sullivan, 2016; Prigatano, 2014).

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## **Abstract**

*Introduction:* self-awareness impairment is a common symptom of patients after suffering acquired brain injury, affecting the rehabilitation process and achievements in terms of patients' daily living functionality.

*Patients and methods:* A systematic review was performed using Scopus and Pubmed databases of scientific articles that address self-awareness in patients with brain injury between 2000 and 2019. Finally, 65 articles were reviewed.

*Results:* As a metacognitive process, self-awareness is linked to other higher order cognitive domains such as executive functions and memory. In recent years, specific intervention programmes for self-awareness have been developed and implemented, and have proved their effectiveness, by using different techniques (i.e psychoeducation and feedback). Considering the importance of assessing the success of the self-awareness interventions in terms of functional improvement, some studies have explored the generalization and transfer of results from those interventions to activities of daily living.

*Conclusions:* research in self-awareness in patients with acquired brain injury has developed significantly in recent years, considering the neuropsychological, psychological and social factors of this phenomenon. The promising future of research in this field points at its inclusion as screening tool in the assessment protocols and, if applicable, its individualized intervention, contributing to an effective global rehabilitation that affects patient's quality of life.



**Chapter IV. “Efficacy of an intervention programme for rehabilitation of awareness of deficit after acquired brain injury: A pilot study”**

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**Chapter V. “Improving self-awareness after acquired brain injury leads to enhancements in patients’ daily living functionality”**

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## **Chapter VI. General Discussion**

In this investigation we addressed the concept of SA in patients with ABI, and its relevance and necessary approach in the patients' rehabilitation process. SA can be considered as a specific characteristic related with the difficulty experienced by patients in reflecting one's true condition in the presence of brain injury and refers to the their inability to recognize deficits or problematic circumstances in daily life (Cheng & Man, 2006). It is one of the common problems found in survivors of ABI and produces significant barriers to recovery being one of the most impeding factors in the rehabilitation process. This ability is also frequently impaired in other pathologies as neurodegenerative diseases (Gainotti, 2018), mental disorders (Poletti et al., 2012), or addictions (Le Berre & Sullivan, 2016).

Impaired SA has been traditionally associated with lesions in the right hemisphere, and in particular with anterior areas of the brain. However, recent years research has emphasized the exploration of brain functioning in terms of connections. Some studies indicate that deficit in SA could be associated with disconnections between relevant regions of different brain networks, as those involved in the dorsal prefrontal cortex (Schmitz et al., 2006) or the fronto-parietal control network (Ham et al., 2014). However, these studies are still inconclusive. A comprehensive consideration of the neuropsychological aspects as well as the psychological and emotional edges of SA suggests that greater volume of brain networks, also including connections with subcortical areas and brain stem regions, may be related with this metacognitive skill (Philippi et al., 2012).

One of the most relevant models of SA, the *Biopsychosocial model of awareness*, reflects that, in fact, it consisted of neuropsychological,

psychological and social factors. They must be considered in terms of different influence on impaired SA in each patient, for an adequate intervention approach (Ownsworth, Clare, et al., 2006). However, other models have proposed different dimensions of SA. While the *Pyramid Model* (Crosson et al., 1989) proposes a hierarchy between intellectual, emergent and anticipatory awareness, The *Dynamic Comprehensive Model of Awareness* (Toglia & Kirk, 2000) only proposes two dimensions at the same level, metacognitive (corresponding to the intellectual awareness of Crosson's models) and online (corresponding to the second two dimension of the first model: emergent and anticipatory). Regardless of the considered model, both the distinction between the knowledge and beliefs that patients have about their status, abilities and performance, as well as their ability to monitor and anticipate errors, are two different aspects of SA to consider to approach at the assessment and at the intervention of patients with ABI.

Three main ways to measure SA has been used in the clinical and research practice (Brown et al., 2019). The first one compares patient's self-evaluations in a questionnaire that asks about their functional abilities, with the same version of the questionnaire completed by a close relative. The second one consisted in a semi-structured patient interview, performed by the clinician who consequently rates the patient's level of awareness based on a clinical judgement. And the last one directly compares self-ratings of patient with objective task performance. These approaches have led to the development of different scales to assess SA, all of them with strengths and weaknesses. The clinician should select the most suitable one according to their objectives and considering patient's characteristics. In this series of studies we employed an *ad-hoc* scale, designed in a semi-structured interview format. It allows measuring the three relevant dimensions of awareness: lesion, deficit and disability (see Annex 4).

Here we present three interrelated studies, one systematic review and two experimental studies with a clear clinical and applied approach to intervene in SA and its relationship with patients' functionality in daily activities.

In the first study we explored, through a systematic review, the state of the literature in three relevant aspects of interest related with SA in patients with ABI: the relationship between SA and cognitive functioning, the existence of specific intervention programmes for improving SA, and the relationship between SA and daily living functionality in these patients. The review included research articles from 2000 to 2019. Sixty-five articles were included once exclusion criteria were applied. This review shows that SA, considered as a metacognitive process, is related with cognitive performance in patients with ABI. In particular, executive functions and episodic memory have a connexion with SA and even a predictive value. The review also deepens in SA interventions, highlighting those techniques (e.g. feedback or psychoeducation) that have proven their effectiveness in terms of SA improvement. Finally, the review shows that although only eleven experimental studies have explored the relationship between improvements in SA and enhancements in functional independence, these suggest a positive correlation between them; an important finding considering that the main objective of any rehabilitation programme should be to enhance the functional independence of these patients.

In general, the review shows that research in SA in patients with ABI has experienced a significant development in the last two decades. Significantly, more recent studies tend to consider the previously mentioned relevant factors of this phenomenon, that are the neuropsychological, the psychological and the social ones. The promising future of research in this field points at its inclusion as screening tool in the assessment protocols and,

if applicable, its individualized intervention, contributing to an effective global rehabilitation that positively impacts patient's quality of life.

In the second study we aimed to assess the effectiveness of a structured intervention programme which was developed from a biopsychosocial approach. This programme was designed to include common therapeutic strategies of proven effectiveness, and was implemented in the CEADAC. In order to evaluate the effectiveness of the intervention programme, a sample of sixty patients with ABI was considered. Half of them (the experimental group) received the specific intervention programme, while the other half (the control group) followed an equivalent rehabilitation approach where they received no specific intervention on SA. An assessment of SA was performed before and after the intervention using an *ad-hoc* scale. Noteworthy, a correlation analysis demonstrate a strong association between the scores provided by our *ad-hoc* scales and those provided by the SADI (Fleming et al., 1996), an standardized and widely recognized SA measure, suggesting that the former is able to provide a valid measure of SA in patients with ABI.

Results from the study showed that patients who received the specific programme demonstrated significant improvement in their level of SA, as compared to the control group. This improvement was observable on all the awareness dimensions considered (injury, deficit and disability). In addition, a correlation analysis showed that patients with lower initial SA were those who achieved a greater degree of improvement following the intervention.

Overall, this study provides evidence in favour of the effectiveness of implementing specific intervention programmes for SA in the context a global rehabilitation process of patients with ABI. The improvement of SA took place in each dimension (injury, deficits and disability), with the last one showing the greatest improvement. The structure and format of the

programme was purposely designed to gradually cover the three dimensions, based on the idea that the increase in SA is progressively acquired. Moreover, the study showed that patients with lower pre-treatment SA were those who benefit most from the programme. This result is of particular interest, since it could allow clinicians to establish a reasoned inclusion criteria of patients in the intervention programme in clinical settings. Unlike previous research, the study presents an extensive description of the intervention programme and the detailed sessions and techniques included, which allow other clinicians to use it.

Despite of the promising results raised in the second experiment, a fundamental aim of any rehabilitation intervention is to increase the level of autonomy and functional independence of the patient. Thus, in the third study, we explored whether the improvement in SA induced by a structured intervention programme in patients with ABI is actually associated with an enhancement in their functional outcomes. This experimental study was performed using a pre- and post-test control group design with a sample of fifty-six patients with ABI randomly assigned to an experimental and a control group. Pre- and post-intervention assessments included SA (using the previously mentioned *ad-hoc* scale) and functional outcome (using the Lawton Instrumental Activities of Daily Living Scale) (Lawton & Brody, 1969).

Results showed that patients who received the intervention programme showed a greater improvement in their level of SA and also in their functional outcome, when compared with those in the control group. Additionally, and in order to confirm the relationship between the degree of SA improvement (as indexed by the difference between post-treatment and pre-treatment scores in the SA scale) and the improvement in functional outcome (indexed by the difference between admission and discharge scores in the Lawton IADL), a correlation analysis between both levels of

improvements was performed. Results from this analysis confirmed a positive correlation which was stronger when the effect of pre-treatment level of SA was considered.

Thus this third study showed that implementing an intervention programme in SA, in the context of a global rehabilitation process of patients with ABI, is useful not only for improving their level of SA but also their functionality in their daily activities. Notwithstanding, the relation between improvement in SA and functional outcome enhancement was reliable when the effect of pre-treatment level of SA was controlled. It suggests that the initial level of SA might be a boundary for achieving meaningful functional outcome enhancements through the intervention programme. It seems reasonable that patients with very low initial SA, despite experiencing large improvements in this dimension, were less likely to achieve a significant post-treatment SA level to lead to a meaningful change in functional independence. Even so, the correlation analyses in the whole group, including patients who did not take part of the SA programme, confirmed that improvements in SA were associated with enhancements in functional independence.

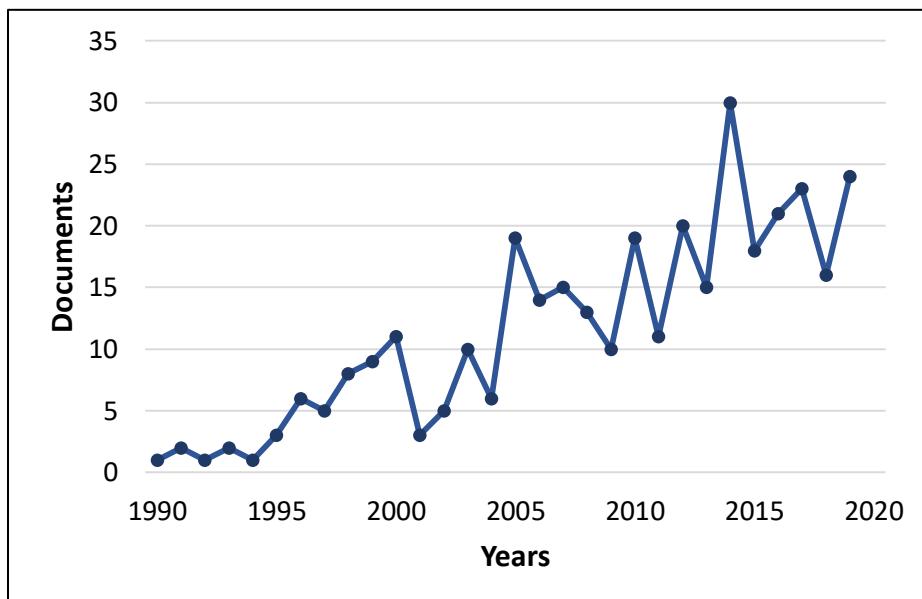
The entire research presented in this series of studies is focus on patients with ABI, an important illness which causes several consequences to patients, their families and the entire society. Relevant changes in our lifestyle have led to a large increase in the incidence of ABI, so much that it is being referred for a long time as a “silent epidemic” (Rusnak, 2013).

Some recent data from European countries like the United Kingdom reveal that ABI incidence has increased by 10% over the past decade. Although improvements in emergency care have resulted in higher rates of survival, neurorehabilitation services for patients are insufficient, and their reintegration into society is limited by a poor understanding of the

consequences of ABI among non-professional population (Menon & Bryant, 2019).

Neurorehabilitation after an ABI is cost effective and can minimise disability (Hayden et al., 2013; Van Heugten et al., 2011). Besides, it is likely that the sooner the patients begin neurorehabilitation, the better their functional outcome (León-Carrión, MacHuca-Murga, Solís-Marcos, León-Domínguez, & Domínguez-Morales, 2013). Therefore, the development and enhancement of new research on intervention techniques and programmes for patients with ABI is essential to improve our understanding of the phenomenon and consequently help patients and their families.

SA has an important influence in the status of patients with ABI, their families' perception, their rehabilitation outcomes and their level of functionality achieved at the end of the rehabilitation process (Evans, Sherer, Nick, Nakase-Richardson, & Yablon, 2005; Ownsworth & Clare, 2006; Sasse et al., 2013). In that sense, the amount of research in the last decades has increased significantly (although it might be considered still scarce, especially compared with other fields) (see Figure 4). This increment reflects the importance of considering SA in patients with ABI and emphasizes the need to keep investigating in this field.



**Figure 4.** Number of documents by years in Scopus database for the search “self-awareness” and “brain injury”.

Performing a correct and precise assessment of SA is the first and necessary step for approach this important aspect of patients with ABI, both in clinical and research fields. Most of the SA measuring scales focus on assessing the intellectual or metacognitive dimension, which is related with the ability to recognize that a particular function or ability is impaired. There are a variety of different approaches and instruments used to assess this SA dimensions, a fact that reveals that there are still a lack of consensus regarding instruments to assess this specific feature of SA (Brown et al., 2019). The development of a standard for the measurement of SA would facilitate comparability across studies, which would produce improved estimates of patient’s impairment and recovery patterns. Given the impact that reduced SA has on rehabilitation and on family and community integration, an appropriate assessment reveals crucial.

Likewise, the emergent and anticipatory dimensions of SA (Crosson et al., 1989) need to be considered for a comprehensive approach (Robertson & Schmitter-Edgecombe, 2015). Strikingly, the development of instruments focused on this online component of SA is a topic that has received less consideration, although valuable developments are being made currently. Of relevance the Post-Coma Unit of Santa Lucia Foundation in Rome (Italy) is working in the validation of a previously developed single scale which allows to measure intellectual, emergent and anticipatory dimensions of SA at a time. Moreover, for each dimension, different emotional-behavioural aspects (not only SA) are evaluated. Thus, the scale also considers denial/false attribution and anosodiaphoria, aspects related with the psychological dimension of SA (Bivona et al., 2019; Gasquoine, 2016; Prigatano, 2014). In addition, this scale specifically assesses the following different areas in each dimension: motor, cognitive, psycho-behavioural and possible others (See Annex 5 for the English version of the scale, still in process of validation). In this way, a single scale that enables a complete approach to SA and its different dimensions, considering its cognitive and emotional/psychological component, would be extremely useful for future work research and applied fields.

The psychological and emotional dimension of SA as well as the metacognitive one, are important for a complete approach of this construct. A further distinction between impaired SA of neurological origin and denial of this deficits and the disability with a psychological origin (Prigatano & Klonoff, 1998) must be taken into consideration, although both may influence the status of the patient at different levels at the same time. It seems reasonable, given the impact of suffering an ABI, that a significant component of the problem in some patients may be psychological in origin. While the lack of SA can be considered a negative symptom of a brain injury, the phenomena of denial has been considered a positive symptom. Clinically,

this aspect may manifest as resistance or even an angry reaction when receiving feedback about deficits, even when done in an appropriate way (cautiously and progressively). This is contrary to the surprise or indifference shown by those with impaired SA of mainly neurological origin. Thus, the psychological component of SA, mainly manifested with denial, is in this sense related to the use of premorbid coping strategy. These mechanisms appear to reduce the anxiety associated with a partial awareness of the loss of function, so that they are not merely an obstacle to overcome but also an adaptive process to protect the patient from the subjective threat of pain (Katz, Fleming, Keren, Lightbody, & Hartman-Maeir, 2002).

Thus, an impaired SA may be due in part to unawareness of neurological origin and, in part, to denial of deficits and disability of psychological origin. Accordingly any patient may be situated anywhere along this unawareness-denial continuum and some of them could show mixed symptoms which fluctuate over time. For this reason, addressing this both aspects in the assessment and the intervention is important for research and clinical progress. The studies presented in this work have mainly focused on the neurological and neurophysiological dimensions of SA, which could be considered a limitation. Nonetheless, we chose to go in depth and focus on these aspects to make our experimental designs and procedures more precise so that results could be more specific and reliable.

Another possible limitation is related with the sample considered in both experimental studies. The inclusion of a variety of brain injury etiologies should be pondered when considering these results. On the one hand, including most frequent etiologies (e.g., traumatic brain injury, stroke, tumor, etc.) in a common sample contributes to make the results more generalizable to the most common profiles of patients who receive cognitive rehabilitation (Bach & David, 2006; Perna, Loughan, & Talka, 2012; Smeets,

Vink, Ponds, Winkens, & van Heugten, 2015; Tornås, Løvstad, Solbakk, Schanke, & Stubberud, 2019). On the other, a mixed sample prevents us from investigating whether different etiologies may present different SA profiles. For these reason some research have focused on specific ABI populations, such as TBI (Hart et al., 2005; Hurst, Ownsworth, Beadle, Shum, & Fleming, 2018; Richardson, McKay, & Ponsford, 2015; Sasse et al., 2013) or stroke (Ekstam et al., 2007; Kersey, Juengst, & Skidmore, 2019; Leung & Liu, 2011). In a similar vein, our sample consisted of patients with ABI who had suffered different degrees of injury severity (severe and moderate). Although this also allows deriving more general conclusions, it would be interesting to investigate whether different levels of severity might be related to differences in the effectiveness of intervention programmes and on their influence in patients' functional independence. Traditionally, severe ABI (as indexed by the Glasgow Coma Scale "GCS" (Teasdale & Jennett, 1974)) has been related with low level of SA (Durette, Plaisier, & Jones, 2008; Richardson et al., 2015). Accordingly, patients with moderate or mild ABI and impaired self-awareness might benefit more from the specific intervention programme through a general enhancement of motivation towards the rehabilitation process.

Despite of the limitations here discussed, this work highlights the importance of evaluating SA in the general assessment of the patient with ABI. Given the major role that the literature attribute to SA on entire rehabilitation process and patients' subsequent functional independence (Ownsworth & Clare, 2006; Ownsworth, Desbois, Grant, Fleming, & Strong, 2006; Schmidt et al., 2011), we suggest that a specific assessment of SA should be included as a fundamental part of the initial evaluation of the patient with ABI.

On the other hand, this work shows that implementing specific intervention programmes for improving SA in patients with ABI is beneficial in terms of SA improving (Villalobos et al., 2018) (For a review see Fleming & Ownsworth, 2006; Leung & Liu, 2011; Lucas & Fleming, 2005; Schrijnemaekers et al., 2014). Moreover, this enhancement in SA extends to daily living activities, making patients more independent and autonomous (Villalobos et al., 2019) (for a review see Engel, Chui, Goverover, & Dawson, 2017). Based on these results, we propose that including such programmes in the rehabilitation of patients with ABI who suffer impaired SA should be a default consideration in the clinical management of these patients.

In addition to specific intervention programmes focused on improving SA, this aspect must always be considered within general rehabilitation of patients with ABI. Several new recommendations are made based on specific aspects of metacognitive strategy training such as prompting for error recognition and providing specific forms of feedback as active components of general cognitive and occupational therapy interventions (Cicerone et al., 2019). Thus, if the implementation of a complete specific programme is not possible, considering metacognition inside the global rehabilitation must provide satisfactory results.

Future research in SA in patients with ABI may follow different directions. On one side, it may continue deepening and developing clinical tools for the assessment and intervention in SA; and on the other, it is also important to delve into the more essential and underlying aspects of the construct to allow subsequent applicable developments. In this sense, our own research line is currently extending to the study of the relationship between cognitive performance and impaired SA in patients with ABI. Specifically, we aim to identify cognitive predictors likely executive function and declarative memory (Goverover, 2004; Morton & Barker, 2010; Noé et

al., 2005; Zimmermann et al., 2017) of SA in patients with ABI along the neuropsychological rehabilitation, from the most early phases to the discharge of the patient from the rehabilitation. Preliminary results suggest that executive measures such as verbal fluency, inhibition and cognitive flexibility, along with episodic memory are best predictors of SA, and that their predictive value changes over the rehabilitation process.

A complementary extension of this work aims to explore the potential moderator role of SA on the already described relation between cognitive impairment and functional independence. Again, preliminary results suggest that higher levels of SA reduce the association between executive impairment and functional independence, highlighting the importance of intervening on SA to increase the use of a wider range of cognitive strategies (Tate et al., 2014).

The present study follows cutting-edges approaches to the concept of SA in patients with ABI from a mainly clinical and applied perspective. Impaired SA is a common and relevant consequence after suffering an ABI thus all professionals who work with this clinical population must consider it as a key aspect of their status and their rehabilitation progress. The inclusion of a SA assessment in any neuropsychological evaluation of patients with ABI seems to be relevant for an appropriate approach. Moreover, intervening specifically for improving SA, inside the global rehabilitation process, could be in many cases the most appropriate form to achieve the greatest benefits of patients. A specific intervention programme is presented, showing the potential to result in beneficial effects improving SA levels, beyond the spontaneous gains which may be expected due to the mere passage of time.

Finally, cognitive rehabilitation should always be directed towards the improvement of everyday functioning, and should include active attempts to promote generalization to functional contexts (Koehler, Wilhelm, &

Shoulson, 2012). Evaluation of rehabilitation effectiveness typically occurs at the impairment level, with the expectation that this will translate into changes in daily functioning. Therefore, an increased emphasis on functional patient outcomes would allow for a more meaningful translation from cognitive domain to patient functioning.

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## **Annexes**

**Annex 1.** Patient form of the Patient Competency Rating Scale (PCRS)

### **Patient Competency Rating (Patient's Form)**

*Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.*

#### **Identifying Information**

Patient's Name:

Date:

#### **Instructions**

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you "had to do". On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

## **Competency Rating**

1	2	3	4	5
Can't do to do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

- \_\_\_\_\_ 1. How much of a problem do I have in preparing my own meals?
- \_\_\_\_\_ 2. How much of a problem do I have in dressing myself?
- \_\_\_\_\_ 3. How much of a problem do I have in taking care of my personal hygiene?
- \_\_\_\_\_ 4. How much of a problem do I have in washing the dishes?
- \_\_\_\_\_ 5. How much of a problem do I have in doing the laundry?
- \_\_\_\_\_ 6. How much of a problem do I have in taking care of my finances?
- \_\_\_\_\_ 7. How much of a problem do I have in keeping appointments on time?
- \_\_\_\_\_ 8. How much of a problem do I have in starting conversation in a group?
- \_\_\_\_\_ 9. How much of a problem do I have in staying involved in work activities even when bored or tired?
- \_\_\_\_\_ 10. How much of a problem do I have in remembering what I had for dinner last night?
- \_\_\_\_\_ 11. How much of a problem do I have in remembering names of people I see often?

- \_\_\_\_\_ 12. How much of a problem do I have in remembering my daily schedule?
- \_\_\_\_\_ 13. How much of a problem do I have in remembering important things I must do?
- \_\_\_\_\_ 14. How much of a problem would I have driving a car if I had to?
- \_\_\_\_\_ 15. How much of a problem do I have in getting help when I'm confused?
- \_\_\_\_\_ 16. How much of a problem do I have in adjusting to unexpected changes?
- \_\_\_\_\_ 17. How much of a problem do I have in handling arguments with people I know well?
- \_\_\_\_\_ 18. How much of a problem do I have in accepting criticism from other people?
- \_\_\_\_\_ 19. How much of a problem do I have in controlling crying?
- \_\_\_\_\_ 20. How much of a problem do I have in acting appropriately when I'm around friends?
- \_\_\_\_\_ 21. How much of a problem do I have in showing affection to people?
- \_\_\_\_\_ 22. How much of a problem do I have in participating in group activities?
- \_\_\_\_\_ 23. How much of a problem do I have in recognizing when something I say or do has upset someone else?
- \_\_\_\_\_ 24. How much of a problem do I have in scheduling daily activities?

- \_\_\_\_\_ 25. How much of a problem do I have in understanding new instructions?
- \_\_\_\_\_ 26. How much of a problem do I have in consistently meeting my daily responsibilities?
- \_\_\_\_\_ 27. How much of a problem do I have in controlling my temper when something upsets me?
- \_\_\_\_\_ 28. How much of a problem do I have in keeping from being depressed?
- \_\_\_\_\_ 29. How much of a problem do I have in keeping my emotions from affecting my ability to go about the day's activities?
- \_\_\_\_\_ 30. How much of a problem do I have in controlling my laughter?

**Annex 2.** Awareness Questionnaire (AQ)

**Awareness Questionnaire**  
**(Patient's Form)**

*Source: Sherer, M., Bergloff, P., Boake, C., High, W., & Levin, E. (1998). The Awareness Questionnaire: Factor structure and internal consistency. Brain Injury, 12(1), 63–68.*

Name: \_\_\_\_\_ Patient :\_\_\_\_\_

Date: \_\_\_\_\_

1	2	3	4	5
Much worse	A little worse	About the same	A little better	Much better

- \_\_\_\_\_ 1. How good is your ability to live independently now as compared to before your injury?
- \_\_\_\_\_ 2. How good is your ability to manage your money now as compared to before your injury?
- \_\_\_\_\_ 3. How well do you get along with people now as compared to before your injury?
- \_\_\_\_\_ 4. How well can you do on tests that measure thinking and memory skills now as compared to before your injury?
- \_\_\_\_\_ 5. How well can you do the things you want to do in life now as compared to before your injury?

- \_\_\_\_\_ 6. How well are you able to see now as compared to before your injury?
- \_\_\_\_\_ 7. How well can you hear now as compared to before your injury?
- \_\_\_\_\_ 8. How well can you move your arms and legs now as compared to before your injury?
- \_\_\_\_\_ 9. How good is your coordination now as compared to before your injury?
- \_\_\_\_\_ 10. How good are you at keeping up with the time and date and where you are now as compared to before your injury?
- \_\_\_\_\_ 11. How well can you concentrate now as compared to before your injury?
- \_\_\_\_\_ 12. How well can you express your thoughts to others now as compared to before your injury?
- \_\_\_\_\_ 13. How good is your memory for recent events now as compared to before your injury?
- \_\_\_\_\_ 14. How good are you at planning things now as compared to before your injury?
- \_\_\_\_\_ 15. How well organized are you now as compared to before your injury?
- \_\_\_\_\_ 16. How well can you keep your feelings in control now as compared to before your injury?
- \_\_\_\_\_ 17. How well adjusted emotionally are you now as compared to before your injury?

### **Annex 3. Self-Awareness of Deficits Interview (SADI)**

## **Self-Awareness Deficit Interview and Scoring**

*Source: Fleming, J. M., Strong, J., & Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure? Brain Injury, 10(1), 1–15. <https://doi.org/10.1080/026990596124674>*

### **Part 1: S-A Deficits**

**Q:** Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you or your abilities has changed?

**Alt:** *Do people who know you well notice that anything is different about you since the accident? What might they notice?*

**Alt:** *What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on/would like to get better?*

### **Prompts:**

Physical abilities (e.g., move arms/legs, balance, vision, endurance)?

Memory/confusion?

Concentration?

Problem-solving, decision-making, organizing and planning things?

Controlling behaviour?

Communication?

Getting along with other people?

Has your personality changed?

Are there any other problems that I haven't mentioned?

Score: CIRCLE 1

0	Cognitive/psychological problems where relevant are reported by patient/client in response to general questioning, or readily acknowledged in response to specific questioning.
---	---

1	Some cognitive/psychological problems reported, but others denied or minimized. Patient/client may have a tendency to focus on relatively minor physical changes (e.g., scars) and acknowledge cognitive/psychological problems only on specific questioning about deficits.
2	Physical deficits only acknowledged; denies, minimizes, or is unsure of cognitive/psychological changes. Patient/client may recognize problems that occurred at an earlier stage, but denies existence of persisting deficits, or may state that other people think there are deficits, but s/he does not think so.
3	No acknowledgement of deficits can be obtained (other than for obvious physical deficits). Or – patient/client will only acknowledge problems that have been imposed on him/her (e.g., not allowed to drive, not allowed to drink alcohol).

Subject Statements (and cues):

## **Part 2: S-A Functional Impact**

**Q:** Does your head injury have any effect on your everyday life? In what way?

### **Prompts:**

Ability to live independently?

Managing finances?

Look after family/manage home?

\*Driving? ***Do you see anything in your current function that would make your driving less safe?***

Work/study?

Leisure/social life?

Are there any other areas of life which you feel have changed/may change?

Score: **CIRCLE 1**

0	Patient/client accurately describes current functional status in independent living, work/study, leisure, home management, driving) and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems
1	Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g., is unable to say because s/he has not tried an activity yet.
2	Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
3	Little acknowledgement of functional consequences can be obtained. The patient/client will not acknowledge problems: except that s/he is not allowed to perform certain tasks. S/he may actively ignore medical advice and may engage in risk-taking behaviours (drinking, driving).

Subject Statements (and cues):

### **Part 3: Ability to set realistic goals**

**Q:** What do you hope to achieve in the next 6 months? Do you have any goals? What are they?

**Alt:** In 6 months' time, what do you think you will be doing? Where do you think you will be?

**Alt:** Do you think your head injury will still be having an effect on your life in 6 months' time? If yes – how? If no – are you sure?

Score: **CIRCLE 1**

0	Patient/client accurately describes current functional status in independent living, work/study, leisure, home management, driving) and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems
1	Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g., is unable to say because s/he has not tried an activity yet.
2	Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
3	Little acknowledgement of functional consequences can be obtained. The patient/client will not acknowledge problems: except that s/he is not allowed to perform certain tasks. S/he may actively ignore medical advice and may engage in risk-taking behaviours (drinking, driving).

Subject Statements (and cues):

\_\_\_\_\_ TOTAL SCORE for 3 parts

**Annex 4.** Awareness of Deficit *ad-hoc* Scale, Spanish version.

<b>ESCALA CONCIENCIA DEL DÉFICIT</b>	
<b>Conciencia de la lesión</b>	
No reconoce haber sufrido una lesión cerebral, accidente, necesitar rehabilitación de ningún tipo	0
No reconoce haber sufrido una lesión cerebral, pero sí reconoce haber sufrido un accidente o estar enfermo	2
Reconoce tener una lesión cerebral sólo ante interrogatorio	4
Explica de manera espontánea lo que le ha ocurrido	6
<b>CONCIENCIA LESIÓN TOTAL (1-6)</b>	
<b>Conciencia del déficit</b>	
No tiene conciencia de tener ninguna dificultad que necesite rehabilitación	0
Reconoce de sólo ante interrogatorio o ejemplos tener dificultades en un área afectada (físicas, sensoriales o cognitivas) pero no en otras que también están afectadas	2
Reconoce de manera espontánea tener dificultades en un área afectada (físicas, sensoriales o cognitivas) pero no en otras que también están afectadas	4
Es capaz de describir dificultades en varias áreas afectadas (físicas, sensoriales o cognitivas), solo ante el interrogatorio o ejemplos, pero no es consciente de otros déficit también importantes	6
Es capaz de describir de manera espontánea dificultades en varias áreas afectadas (físicas, sensoriales o cognitivas), pero no es consciente de otros déficit también importantes	8
Conoce y es capaz de describir sus principales dificultades con un poco de ayuda o ejemplos	10
Conoce y es capaz describir sus principales dificultades de manera espontánea	12
<b>CONCIENCIA DE DÉFICIT TOTAL (1-12)</b>	

<b>Discapacidad</b>	
(Puntuar 2 si su perspectiva es realista y 0 si no lo es)	
Conducir (si no conduce preguntar por montar en bici)	0 – 2
Preparar la cena o la merienda	0 – 2
Hacer las tareas de la casa	0 – 2
Cuidar de un niño pequeño	0 – 2
Trabajar o estudiar	0 – 2
Vivir sólo	0 – 2
<b>CONCIENCIA DISCAPACIDAD TOTAL (0-12)</b>	
<b>ESCALA TOTAL (0-30)</b>	

**Annex 5. English version of Italian Self-Awareness Scale**

**Self-Awareness Scale (SAS)**

Giuli Ferri, Tiziana Fontanelli, Francesca Amadori, Laura Cellupica,  
 Manuela Iannetti, Paola Lo Sterzo, Cristiana Lucarelli, Susanna  
 Lucatello, Sara Masella, Elisabetta Mutolo, Fabiana Mungiello, Chiara  
 Picciuca, Rita Formisano, Maria Paola Ciurli, Alberto Costa e Umberto  
 Bivona

INTELLECTUAL		Yes (0)	With cue (1)	No (2)	N.A.
Self-Awareness	<p>Recognizes the presence of current difficulties (specify the difficulties already known to the patient on the <b>basis of the NPS report</b>, highlighted by <b>clinical observation or reported by the caregiver</b>):</p> <p><i>Motor:</i> _____</p> <p><i>Cognitive:</i> _____</p> <p><i>Psycho-behavioural:</i> _____</p> <p><i>Others (specify which ones):</i> _____ _____</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<p>Recognizes the <b>functional implications</b> of one's difficulties:</p> <p><i>Motor</i> _____</p> <p><i>Cognitive</i> _____</p> <p><i>Psycho-behavioural</i> _____</p> <p><i>Others</i> _____</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Denial</b>	<p><b>Being aware of changes, recognizes a connection with the traumatic event due to difficulties:</b></p> <p style="text-align: center;"><i>Motor</i>  <i>Cognitive</i>  <i>Psycho-behavioural</i></p> <p><i>Others</i> _____</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			
<b>Anosodiaphoria</b>	<p>Demonstrates an emotional involvement <b>in relation to one's abilities</b>:</p> <p style="text-align: center;"><i>Motor</i>  <i>Cognitive</i>  <i>Psycho-behavioural</i></p> <p><i>Others</i> _____</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			

EMERGENT		Yes (0)	With cue (1)	No (2)	N.A
<b>Self-Awareness</b>	<p><b>When they occurs, recognizes the presence of difficulties:</b></p> <p><i>Motor (specify which ones):</i> _____</p> <p><i>Cognitive (specify which ones):</i> _____</p> <p><i>Psycho-behavioural (specify which ones):</i> _____</p> <p><i>Others (specify which ones):</i> _____</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Denial</b>	<p>Recognizing performance difficulties to the proposed tasks, <b>also recognizes a connection</b> with the traumatic event due to the difficulties:</p> <p><i>Motor</i> _____</p> <p><i>Cognitive</i> _____</p> <p><i>Psycho-behavioural</i> _____</p> <p><i>Others</i> _____</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Anosodiaphoria</b>	<p>Demonstrates an emotional involvement <b>in relation to his performance</b>, at the level:</p> <p><i>Motor</i> _____</p> <p><i>Cognitive</i> _____</p> <p><i>Psycho-behavioural</i> _____</p> <p><i>Others</i> _____</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ANTICIPATORY		Yes (0)	With cue (1)	No (2)	N.A
<b>Self-Awareness</b>	Is able to <b>recognize the problematic</b> nature of a task with respect to his own deficits at the level:  <i>Motor</i> <i>Cognitive</i> <i>Psycho-behavioural</i> <i>Others</i> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Is able to <b>set realistic goals</b> in relation to his own difficulties at level:  <i>Motor</i> <i>Cognitive</i> <i>Psycho-behavioural</i> <i>Others</i> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Declares the <b>need for aids / compensation / strategies</b> to avoid having difficulties at the level:  <i>Motor</i> <i>Cognitive</i> <i>Psycho-behavioural</i> <i>Others</i> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>Effectively uses</b> aids / compensation / strategies to avoid having difficulty at the level:  <i>Motor</i> <i>Cognitive</i> <i>Psycho-behavioural</i> <i>Others</i> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<p>Using aids / compensation / strategies in the rehabilitation context, <b>he/she is able to generalize to all the contexts in which he/she acts</b>, at the level:</p> <p><i>Motor</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Cognitive</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Psycho-behavioural</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Others</i> _____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>			
	<b>ANTICIPATORY (continuation)</b>	Yes (0)	With cue (1)	No (2)
<b>Denial</b>	<p>Recognizing probable difficulties in daily life related to one's deficits, <b>recognizes a connection with the traumatic event with respect to these difficulties</b>:</p> <p><i>Motor</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Cognitive</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Psycho-behavioural</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Others</i> _____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>			N.A
<b>Anosodiaphoria</b>	<p>In relation to probable future difficulties in daily life, <b>it demonstrates an emotional involvement</b> that is congruent with one's own abilities:</p> <p><i>Motor</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Cognitive</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Psycho-behavioural</i> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p><i>Others</i> _____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>			



## Annex 6. First page of the original article “La conciencia de déficit como proceso clave en la rehabilitación de los pacientes con daño cerebral adquirido: revisión sistemática”.

ORIGINAL

### Conciencia de déficit como proceso clave en la rehabilitación de pacientes con daño cerebral adquirido: revisión sistemática

Dolores Villalobos, Álvaro Bilbao, Francisco López-Muñoz, Javier Pacios

**Introducción.** La afectación de la conciencia de déficit es un síntoma habitual de los pacientes que sufren una lesión cerebral, que afecta al proceso rehabilitador y a los logros en términos de independencia funcional del paciente.

**Pacientes y métodos.** Se realizó una revisión sistemática en las bases bibliográficas Scopus y PubMed de los trabajos científicos que han abordado la conciencia de déficit en pacientes con daño cerebral entre 2000 y 2019. Finalmente se revisaron 65 artículos.

**Resultados.** La conciencia de déficit como proceso metacognitivo está ligada a otros procesos cognitivos de orden superior, como las funciones ejecutivas y la memoria. En los últimos años, se han diseñado e implementado programas de intervención específicos sobre conciencia de déficit que han demostrado su eficacia mediante la incorporación de diferentes técnicas (por ejemplo, psicoeducación y feedback). Ante la necesidad de evaluar el éxito de la intervención sobre la conciencia de déficit en términos de mejora funcional, algunos trabajos han estudiado la generalización y la trasferencia de los resultados de la intervención sobre la conciencia de déficit a las actividades de la vida diaria.

**Conclusiones.** La investigación en conciencia de déficit en pacientes con daño cerebral se ha desarrollado de forma significativa en los últimos años, considerando los factores neuropsicológicos, psicológicos y sociales de este fenómeno. Su futuro prometedor apunta hacia su incorporación como cribado en los protocolos de evaluación y, en su caso, su intervención de forma específica, lo que contribuirá a una rehabilitación eficaz que repercuta en la calidad de vida de los pacientes.

**Palabras clave.** Conciencia de déficit. Daño cerebral adquirido. Funcionalidad. Metacognición. Neuropsicología. Rehabilitación.

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#### Introducción

Los pacientes con daño cerebral adquirido (DCA) presentan habitualmente falta de conciencia de déficit (*self-awareness*), tanto si éste se produce por un accidente traumático [1] como por un accidente cerebrovascular [2]. Estos pacientes no entienden las dificultades físicas, cognitivas, comportamentales y emocionales causadas por la lesión, y la incapacidad que éstas le provocan, y no consideran las repercusiones que sus déficits tienen en su capacidad funcional en las actividades de la vida diaria [3].

La afectación de la conciencia de déficit tras un DCA parece estar relacionada con algunas variables clínicas, que resulta interesante conocer. La gravedad de la lesión parece influir en la afectación de la conciencia de déficit, y ésta está más alterada en los pacientes con daños más graves [4-6]. Asimismo, el tiempo transcurrido desde la lesión también parece ser un factor influyente, dado que la conciencia de déficit aumenta con el paso del tiempo [7]. De este modo, los pacientes con el daño más reciente tienen más afectación de la conciencia [8], mientras que son los pacientes con más tiempo desde la lesión los

que muestran una conciencia de los déficits, especialmente motores, más ajustada a la realidad [6].

En pacientes con DCA, una adecuada conciencia de déficit está relacionada con la motivación hacia el proceso rehabilitador y con el éxito de éste [9,10], de manera que menores niveles de conciencia de déficit se asocian con un menor grado de independencia funcional [11]. Sin embargo, una adecuada conciencia de déficit se asocia a una baja autoestima y un mayor nivel de depresión [12], a un mayor nivel de estrés [13] y a una menor percepción de calidad de vida [14], si bien se ha sugerido que estas relaciones podrían desaparecer a largo plazo [15].

En este sentido, se ha planteado que un adecuado abordaje de los problemas en conciencia de déficit en pacientes con DCA debe considerar no sólo los aspectos neuropsicológicos, sino también los puramente psicológicos. Si bien las alteraciones cognitivas en estos pacientes desempeñan un papel fundamental en la presencia de una conciencia de déficit reducida, la lesión cerebral y la nueva situación que ésta comporta para el paciente probablemente desencadenan mecanismos psicológicos de negación, relacionados con la evitación de la angustia



## Annex 7. First page of the original article “Efficacy of an intervention programme for rehabilitation of awareness of deficit after acquired brain injury: A pilot study”.

BRAIN INJURY  
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### Efficacy of an intervention programme for rehabilitation of awareness of deficit after acquired brain injury: A pilot study

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#### ABSTRACT

**Background:** Impaired Awareness of Deficit (AD) is a frequent symptom after suffering acquired brain injury (ABI) that severely influences patients' daily lives.

**Primary Objective:** Pilot study to assess the effectiveness of a structured intervention programme which was developed from a biopsychosocial approach, and relied on common therapeutic strategies of proven effectiveness.

**Methods:** We assessed the effectiveness of our intervention on a sample of 60 patients with ABI, 30 of whom received the specific AD intervention programme, while the other 30 followed an equivalent rehabilitation approach where they received no specific intervention on AD. AD were assessed before and after the specific intervention on AD through an ad-hoc designed questionnaire.

**Results:** This study reports that patients who received the proposed programme demonstrated significant improvement in their level of AD, as compared to the control group. This improvement was observable on all the proposed dimensions of awareness. Interestingly, results from correlation analysis also showed that patients with lower initial AD were those who exhibited a greater degree of improvement following the intervention.

**Conclusions:** This research provides evidence in favour of the effectiveness of implementing an intervention programme for AD in the context a global rehabilitation process for patients with ABI.

#### ARTICLE HISTORY

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**KEYWORDS**  
Self-awareness; awareness of deficit; brain injury; rehabilitation

### Introduction

When a person suffers acquired brain injury (ABI), there are often many residual physical symptoms as well as sensory, cognitive, behavioural and emotional deficits. One impairment commonly seen after ABI is in Awareness of Deficit (AD).

Impaired AD is a complex phenomena and is often referred to in the literature using other terms such as self-awareness or anosognosia, the latter usually being used as a synonym for lack of AD (1). George Prigatano defined self-awareness in first instance as the “*capacity to perceive oneself in relatively objective terms while keeping a sense of subjectivity*”; thus self-awareness or awareness of higher mental functions involves an integration of thoughts and feelings (2). Also, this author proposes a definition of impaired AD as “the clinical phenomena in which a brain dysfunctional patient does not appear to be aware of impaired neurological or neuropsychological function, which is obvious to the clinician and other reasonably attentive individuals” (3).

Scientific research has emphasised the importance of considering self-awareness as a multidimensional construct (4). Initial investigations on this topic proposed a hierarchical model, the Pyramid Model of Self-Awareness, with three separate levels: intellectual, emergent and anticipatory awareness (5). Later on, this model has acquired more complexity, leading to the development of the Dynamic Comprehensive Model of Awareness (4), which primarily focuses on the relationship between different aspects of metacognition and consciousness. In this model, the term “online awareness” includes components that come to action whilst performing the task as well as after doing it. This encompasses the ability to change thoughts and beliefs during the execution of the task (self-monitoring), error detection (error-monitoring) and proper adjustment of the performance (self-regulation). The concept of metacognition refers to the level of awareness prior to the performance of a task, including knowledge and beliefs about oneself and the individual's perception of his own functioning. In our study, we mainly focus on metacognition of patients who have suffered brain injury. This corresponds to the initial concept of intellectual awareness, at the base of the Pyramid Model of Self-Awareness, on which the other dimensions of online-awareness depend (5).

From a clinical point of view, AD has often been defined as the ability to recognise deficits or problems caused by a brain lesion (5). Similarly, keeping in mind the important relationship that arises between this concept and patients functional status, it may be noted that AD stems from objective knowledge, being the ability to relate this knowledge to the person's

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**Annex 8. First page of the original article “Improving self-awareness after acquired brain injury leads to enhancements in patients’ daily living functionality”**

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BRIEF REPORT

## Improving Self-awareness After Acquired Brain Injury Leads to Enhancements in Patients’ Daily Living Functionality

Dolores Villalobos<sup>1,2</sup> , Álvaro Bilbao<sup>3</sup>, Francisco López-Muñoz<sup>1,4</sup> and Javier Pacios<sup>5\*</sup> 

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### Abstract

**Objective:** To explore whether the improvement in self-awareness induced by a structured intervention programme in patients suffering a brain injury is associated with an enhancement in their functional outcomes.

**Method:** This study uses a pre- and post-test control group design with a sample of 56 patients with acquired brain injury randomly assigned to an experimental and a control group. Pre- and post-intervention measurements were self-awareness (using a previously developed scale) and functional outcome (using the Lawton Instrumental Activities of Daily Living Scale).

**Results:** Patients who received the intervention programme showed a greater improvement in their self-awareness level and functional outcome than patients in the control group. Additionally, the correlation analyses between improvements at both measures showed a relation between improvement in self-awareness and improvement in functional outcome, especially when the pre-treatment self-awareness level was considered.

**Conclusions:** Implementing an intervention programme in self-awareness, in the context of a global rehabilitation process of patients with acquired brain injury, is useful for improving their self-awareness level and the functionality in their daily activities.

**Keywords:** Awareness of deficit; brain damage; neuropsychology; rehabilitation; treatment outcome; activities of daily living

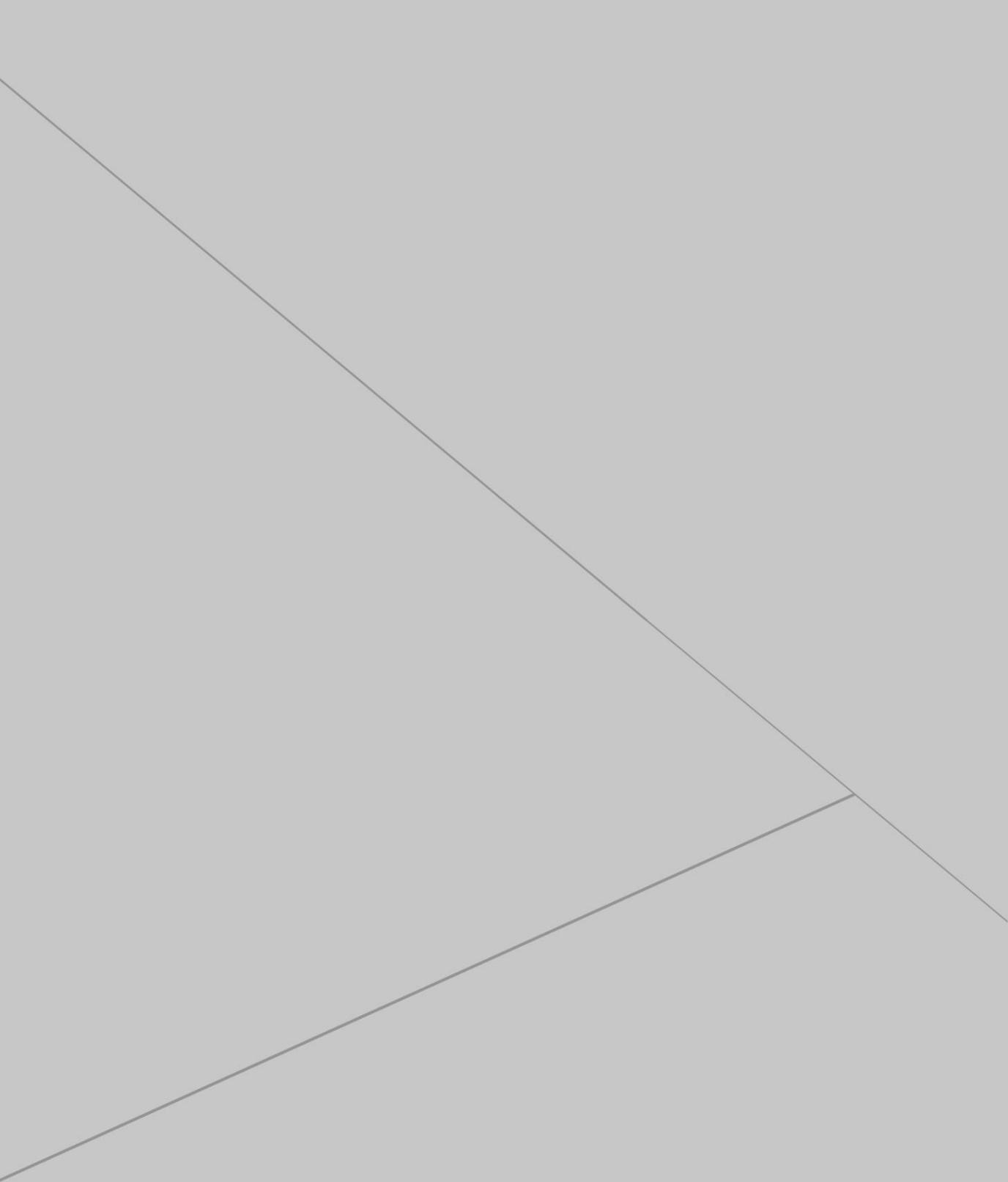
### Introduction

Self-awareness can be defined as the ability to recognize deficits caused by a neurological injury or underlying brain pathology. This is one of the most complex impairments after an acquired brain injury (ABI) (Geytenbeek, Fleming, Doig, & Ownsworth, 2017). Impaired self-awareness involves decreased understanding of the functional impact of impairments caused by the brain injury. Consequently, patients do not perceive the need and benefits of engaging in therapy and thus experience decreased motivation and poor acceptance of the use of compensatory strategies. Finally, this may lead to difficulties achieving and maintaining productive and independent living (Schmidt, Lannin, Fleming, & Ownsworth, 2011).

Over the last few years, a variety of intervention programmes using different techniques and methodologies have been developed, which aim to increase the level of self-awareness in

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