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Email: praxispsy@mail.udp.cl

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EDITORIAL

Hoy existe una creciente conciencia respecto al rol central que nuestro cerebro juega en numerosos procesos psicológicos y sociales. Los avances tecnológicos nos han permitido comprender su intrincada estructura y composición, así como develar progresivamente su funcionamiento eléctrico y químico. Ninguna de las complejas conductas que realizamos como seres humanos, o de los sutiles sentimientos que experimentamos, puede ser alienado de la materialidad de este órgano que sólo pesa un kilo y medio, pero que supera en sofisticación a cualquier supercomputadora jamás creada. No es de extrañar entonces que el estudio del cerebro, comúnmente referido como neurociencia, haya irrumpido tempestuosamente en los textos y mallas de numerosas profesiones relacionadas a la salud, ciencias sociales y humanidades. Durante los últimos años en Chile también hemos visto surgir progresivamente laboratorios y centros dedicados al estudio del cerebro humano, así como programas de formación en neurociencia y disciplinas afines. No obstante, este fervor por el cerebro ha sido foco de importante polémica, generando alarmas respecto a los peligros del “neuro-reduccionismo” o al poder que lo “neuro” ha adquirido como un discurso por sobre otras fuentes de conocimiento. El neuromarketing, la neuroeducación o la neuro terapia son todos ejemplos de este furor, furor que refleja un anhelo ancestral de los seres humanos de acceder finalmente a una verdad absoluta. Probablemente Jung diría que hoy lo “neuro” ocupa un lugar arquetípico para el hombre postmoderno occidental. Por otro lado, el gran interés del público por lo “neuro” se ha debido a la vulgarización del conocimiento neurocientífico (*vulgarización*: exponer una ciencia o materia técnica en forma fácilmente accesible al común de las personas). Esto ha sido inevitable consecuencia de una sociedad hiperconectada donde el acceso al conocimiento progresivamente se ha democratizado y transformado en bien de consumo.

Este es el contexto en el cual nace este número temático. Un momento histórico donde las neurociencias han permitido avanzar en comprender y replicar la mente humana. Este número temático nace además en un nicho particularmente único, la revista *PraxisPsy* de la Facultad de Psicología de la Universidad Diego Portales. *PraxisPsy* intenta reflejar el espíritu de esta casa de estudios, un espíritu que concibe la psicología como un conjunto de saberes en constante tensión e influencia mutua. En *PraxisPsy* cohabitan -no sin roces ni tensiones- tres saberes o tradiciones que han formado parte de la historia de nuestra escuela: la psicología social crítica, la psicología clínica/psicoanálisis, y la neurociencia humana. Nuestra visión como escuela -al menos como yo lo interpreto- es que los roces y tensiones entre estos saberes son la esencia y el valor de nuestra proteica psicología. El nombre *PraxisPsy* es aquí afortunado debido a sus múltiples significados históricos: a) como la actividad por medio del cual los seres humanos crean y cambian el mundo y a ellos mismos; b) como la compleja relación entre teoría y práctica en psicología clínica; c) como la capacidad mental de controlar voluntariamente nuestro cuerpo para interactuar con el ambiente y sus objetos (praxia).

Este número temático está dedicado a una pequeña parcela de la neurociencia: la neuropsicología, y en específico, el trabajo terapéutico que realizan profesionales de la salud para ayudar a personas y familias luego de un daño cerebral -adquirido o progresivo- a retornar a la comunidad. Esta disciplina se conoce como Rehabilitación Neuropsicológica. Cuando la base material de la mente se daña pueden ocurrir numerosos cambios en

el ser humano, cambios que afectan radicalmente aspectos de su existencia como el producir, amar y jugar. Estos cambios - físicos, cognitivos, socio emocionales o conductuales- impactan no sólo al individuo que los padece, sino también a quienes le rodean en su círculo familiar y social. La frecuencia de estos problemas en nuestro país es abrumadora, tanto así que constituye un problema de salud pública. Más de 37.000 personas al año egresan de hospitales públicos y privados con el diagnóstico de una lesión cerebral adquirida (Accidente Cerebro Vascular, Traumatismo Craneano, Encefalitis, Meningitis, etc). Se espera que al año 2025 vivan en Chile más de 270.000 personas con un diagnóstico de trastorno neurocognitivo mayor o demencia.

El cuidado de personas con daño cerebral adquirido o progresivo presenta desafíos tanto diagnósticos como terapéuticos. Los artículos de este número temático contribuyen a cada uno de estos desafíos. El artículo de Ramos et al., por ejemplo, presenta el desarrollo de una prueba novedosa (TELE) para evaluar un tipo de problema cognitivo altamente prevalente en personas con demencia -alteraciones ejecutivas-, pero particularmente difícil de pesquisar en quienes poseen una baja escolaridad. Varios artículos contribuyen a los desafíos diagnósticos por medio de caracterizar déficits específicos luego de una lesión cerebral, así como explorar su impacto en la rehabilitación. Así, Milders y Yeates caracterizan errores de mentalización en una muestra de personas con lesión cerebral y comparan su rendimiento con personas neurotípicas. De forma similar, Schönberger, Yeates y Hobbs exploran la relación existente entre déficits de la cognición social y alianza terapéutica con profesionales de la rehabilitación. Respecto a los desafíos terapéuticos el artículo de García-Molina et al., nos presenta una reseña histórica del Instituto de Rehabilitación Guttmann, centro clínico español que ha sido una poderosa influencia en el desarrollo de la rehabilitación de personas con lesión cerebral en Latinoamérica. En su artículo, García-Molina y su equipo rastrean los orígenes e influencias históricas del Guttmann, así como el desarrollo de un modelo de rehabilitación holista para esta población. Prigatano, Walls y Meites nos ofrecen un interesante artículo teórico clínico en el cual se propone el uso de enfoques terapéuticos jungianos para abordar las necesidades psicológicas de personas diagnosticadas con demencia tipo Parkinson. La originalidad de este artículo radica en el trasplante de ideas psicoanalíticas Jungianas, utilizadas históricamente en lesión cerebral, a esta nueva población, así como la consideración de la relación del proceso de duelo con el avance progresivo de la enfermedad. El artículo de Yeates et al., reporta interesantes resultados de un piloto que utiliza intervenciones orientales mente-cuerpo (Tai-chi) en contextos de neurorrehabilitación. Este artículo es un claro ejemplo del desarrollo de líneas terapéuticas no tradicionales en la rehabilitación de personas con lesión cerebral, las cuales no sólo tienen un impacto en variables físicas (balance, movilidad), sino también en marcadores de bienestar psicológico de personas que residen en la comunidad. Finalmente, el texto de Grasso-Cladera y Salas se ubica en la intersección entre diagnóstico e intervención, ofreciendo una revisión sobre dificultades invisibles luego de una lesión cerebral, las cuales tienden a ser subdiagnosticadas y malentendidas tanto por sobrevivientes, personal de salud como familiares. En su texto, las autoras revisan la literatura con el fin de determinar qué es "lo invisible", así como las estrategias terapéuticas que han sido propuestas para su abordaje.

Espero que lectores y lectoras valoren este grupo de artículos como una contribución al desarrollo de la Neuropsicología y Rehabilitación Neuropsicológica. Este número

temático es asimismo una invitación a todos quienes trabajan en estas disciplinas, y en neurociencia en general, a considerar *PraxisPsy* como un posible hogar para sus publicaciones. Espero de todo corazón que *PraxisPsy* se constituya en el futuro en una revista de referencia para la neurociencia humana, neuropsicología y rehabilitación neuropsicológica en Chile y Sudamérica.

Christian Salas, Ph.D.
Editor Número Temático
Neuropsicólogo Clínico
Centro Neurociencia Humana y Neuropsicología (CENHN)
Director Unidad de Neuropsicología Clínica, UDP
Director SERebros
christian.salas@udp.cl

ARTÍCULO DE REVISIÓN

INSTITUT GUTTMANN: 40 AÑOS DE REHABILITACIÓN
NEUROPSICOLÓGICA (1983-2023)INSTITUT GUTTMANN: 40 YEARS OF
NEUROPSYCHOLOGICAL REHABILITATION (1983-2023)ALBERTO GARCÍA-MOLINA^{*1,2,3}, TERESA ROIG-ROVIRA^{1,2,3}, ROCÍO SÁNCHEZ-CARRIÓN^{1,2,3}, PABLO RODRÍGUEZ-
RAJO^{1,2,3}, CELESTE APARICIO-LÓPEZ^{1,2,3}, MIGUEL ESPÍÑA-BOU^{1,2,3}, ANTONIA ENSEÑAT-CANTALLOPS^{1,2,3}

* Correspondencia:
Alberto García-Molina
agarciam@guttmann.com

Reconocimientos:

Multitud de estudiantes se han formado al lado de los profesionales de la Unidad de Neuropsicología de Institut Guttmann. Les hemos transmitido nuestra forma de entender la rehabilitación. Ellos han contribuido a mejorar nuestro trabajo asistencial.

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En el año 1983 se crea la Unidad de Neuropsicología del Institut Guttmann (Barcelona, España); con la finalidad de facilitar tratamiento rehabilitador a personas con lesiones cerebrales. Su modelo integral de rehabilitación neuropsicológica, fundamentado en una visión holística de la persona, comprende cuatro ámbitos: cognición, conducta, emoción e identidad. Más allá de la persona afectada, también proporciona asistencia a sus familiares. Los objetivos del programa de intervención son: (1) favorecer la estabilidad conductual de la persona; (2) promover la recuperación de procesos cognitivos alterados; (3) mejorar la capacidad funcional, pese a la existencia de déficits subyacentes; (4) facilitar el ajuste emocional a los cambios generados por las lesiones neurológicas; (5) asistir, y acompañar, a la persona en su tránsito hacia una nueva identidad; y (6) proporcionar educación y apoyo emocional a la familia. Este trabajo tiene como objetivo recapitular la historia de la Unidad de Neuropsicología de Institut Guttmann, con motivo de su cuarenta aniversario (1983-2023), y describir su modelo integral de rehabilitación neuropsicológica.

Palabras clave: daño cerebral, rehabilitación neuropsicológica, cognición, emoción, identidad.

In 1983 the Neuropsychology Unit of the Institut Guttmann (Barcelona, Spain) was created with the aim of providing rehabilitation treatment to people with brain injuries. Its comprehensive model of neuropsychological rehabilitation, based on a holistic view of the person, comprises four areas: cognition, behavior, emotion, and identity. Beyond the affected person, it also helps family members. The objectives of the intervention program are: (1) to enhance the person's behavioral stability; (2) to promote the recovery of altered cognitive processes; (3) to improve functional capacity, despite the existence of underlying deficits; (4) to facilitate emotional adjustment to the changes generated by neurological lesions; (5) to assist, and guide, the person in his or her transition to a new identity; and (6) to provide education and emotional support to the family. This paper aims to recapitulate the history of the Neuropsychology Unit of the Institut Guttmann, on its fortieth anniversary (1983-2023), and to describe its comprehensive model of neuropsychological rehabilitation.

Key words: brain injury, neuropsychological rehabilitation, cognition, emotion, identity.

¹. Institut Guttmann, Institut Universitari de Neurorehabilitació adscrit a la UAB, Badalona, Barcelona.

². Fundació Institut d'Investigació en Ciències de la Salut Germans Trias i Pujol, Badalona, Barcelona.

³. Universitat Autònoma de Barcelona, Bellaterra.

INTRODUCCIÓN

La segunda mitad del siglo XX es testigo de un cambio de paradigma, sin precedentes, en las políticas sanitarias de los países occidentales: deciden aplicar a la población civil con lesiones neurológicas las técnicas de rehabilitación reservadas, hasta ese momento, al personal militar (García-Molina & Enseñat-Cantalops, 2019). En Finlandia, el Hospital Universitario de Helsinki organiza un servicio de rehabilitación para ictus y el Centro de Rehabilitación Käpylä para traumatismos craneoencefálicos (Nybo & Hokkanen, 2003). El *Sunnaas Rehabilitation Hospital* de Noruega alberga un servicio para tratamiento multidisciplinar del ictus, mientras que el *Rivermead Rehabilitation Centre* (Inglaterra) atiende a pacientes con lesiones cerebrales adquiridas. A principios de la década de 1970, Leonard Diller (1924-2019) investiga la utilidad de un programa experimental de entrenamiento cognitivo en pacientes con ictus. Los resultados son tan positivos que, poco después de finalizar el proyecto, se incorpora a la cartera de servicios del *Institute of Rehabilitation Medicine* (Nueva York).

En 1978 Yehuda Ben-Yishay (1933-2021), colaborador de Diller, crea un programa de rehabilitación neuropsicológica fundamentado en el marco teórico de Kurt Goldstein (1878-1965) (García-Molina & Peña-Casanova, 2022). Este neurólogo alemán defiende el abordaje terapéutico simultáneo de los déficits cognitivos, emocionales y conductuales. Sostiene que los enfoques centrados exclusivamente en la cognición son inadecuados; enfatizando la importancia de prestar atención a las necesidades personales y sociales de los pacientes, así como de su estado emocional.

El mismo año en el que Ben-Yishay implementa su programa en New York, Mira Ashby (1922-2005) funda la *Ashby House* en Toronto (Canadá): iniciativa pionera en la rehabilitación comunitaria de personas con lesiones cerebrales. En 1983 Lance E. Trexler¹ participa en la creación del *Center for Neuropsychological Rehabilitation*, situado en el *Community Hospital* de Indianapolis (Indiana). Entre 1979 y 1985, George

P. Prigatano (n. 1944) desarrolla un programa de rehabilitación neuropsicológica para pacientes con traumatismos craneoencefálicos en el *Presbyterian Hospital* de Oklahoma City (Oklahoma). En 1985 se traslada al *Barrow Neurological Institute* (Phoenix, Arizona) donde organiza, junto a Pamela S. Klonoff, un programa de características similares. Anne-Lise Christensen (1927-2018) funda, en 1985, el *Center for Hjernesgade* en Copenhague (Dinamarca). El primer centro europeo dedicado exclusivamente a la rehabilitación neuropsicológica post-aguda de pacientes con traumatismos craneoencefálicos. En noviembre de 1996 se inaugura el *Oliver Zangwill Center* en Ely (Inglaterra), -gracias a la perseverancia y tesón de Barbara A. Wilson-.

En 1983 Institut Guttmann se convierte en la primera institución española que desarrolla un programa de rehabilitación neuropsicológica para pacientes con lesiones cerebrales. Casi una década después, en otoño de 1992, se inaugura la Unidad de Hospitalización de Daño Cerebral del Hospital Aita Menni de Mondragón (Guipúzcoa). Cinco años después, en 1997, el neuropsicólogo José León Carrión y la Doctora M^a del Rosario Domínguez Morales fundan en Sevilla el Centro de Rehabilitación de Daño de Cerebral NeuroCRECER. Juan Manuel Muñoz-Céspedes (1965-2005) lidera, en 1999, la creación de la unidad ambulatoria de daño cerebral del Hospital Beata María Ana (Madrid), centro hospitalario integrado en la Red Menni de Daño Cerebral. El 13 de junio de 2002 se inaugura en Madrid el Centro de Referencia Estatal de Atención al Daño Cerebral. Este trabajo tiene como objetivo recapitular la historia de la Unidad de Neuropsicología de Institut Guttmann con motivo de su cuarenta aniversario (1983-2023) y describir, de forma general, su modelo integral de rehabilitación neuropsicológica.

INSTITUT GUTTMANN

El 27 de noviembre de 1965 se inaugura, en Barcelona, el primer hospital español dedicado al tratamiento y rehabilitación integral de personas afectadas por una lesión medular (Sarrias et al., 1998). Recibe el nombre de Institut Guttmann en honor al neurocirujano alemán Ludwig Guttmann (1899-1980), discípulo de Otfried Foerster (1873-1941). Considerado uno de los neurocirujanos más brillantes de Alemania, en los prolegómenos de la Segunda Guerra Mundial, Guttmann se ve obligado a exiliarse a Inglaterra por su condición judía. Durante la guerra, es el responsable de la unidad de lesiones medulares del Hospital de Stoke Mandeville (Buckinghamshire, Inglaterra). Guttmann

1 En 1982 Trexler edita un volumen seminal titulado *Cognitive Rehabilitation: Conceptualization and Intervention*. Este monográfico compendia las ponencias de la conferencia "Modelos y técnicas de rehabilitación cognitiva" celebrada un año antes en Indianapolis. Otras obras clásicas sobre rehabilitación neuropsicológica, de la década de 1980, son *Neuropsychological rehabilitation after brain injury* de Prigatano y colaboradores (1986), *Neuropsychological Rehabilitation* de Meier, Benton y Diller (1987) o *Introduction to Cognitive Rehabilitation* de Sohlberg y Mateer (1989).

realiza avances significativos en el tratamiento de las lesiones medulares y ayuda a promover el bienestar físico y social de innumerables pacientes.

En 1964, Guillermo González Gilbey (1926-1987), promotor y fundador del Institut Guttmann, ofrece al Dr. Miquel Sarrias Domingo (1930-2002) la dirección médica del centro (Sarrias, 1995). Sarrias acepta el encargo y viaja hasta Inglaterra para formarse junto a Guttman en el Hospital de Stoke Mandeville. El equipo asistencial del recién fundado instituto está constituido por Miquel Sarrias (médico), Montserrat Marsans (enfermera) y Patricia Bowerbank (fisioterapeuta). Progresivamente, alrededor de este núcleo original, se conforma un equipo multidisciplinar interesado en el tratamiento médico-rehabilitador de las lesiones medulares. En 1985 la plantilla está formada por 176 profesionales asistenciales y no asistenciales.

en septiembre de 1967 la totalidad del edificio. Conscientes de la necesidad de proporcionar a los pacientes una atención integral, en 1970 se crea el Departamento Psico-social, formado por Mercè Camprubí Freixas (trabajadora social) y Lluïsa Curcoll Gallemí (psicóloga).

En 1997 se crea la Unidad de Daño Cerebral, bajo la dirección de la Dra. Montserrat Bernabéu Guitart, especialista en medicina física y rehabilitación (Vidal & Bernabéu, 2009). Su misión es estandarizar el tratamiento rehabilitador de las personas con lesiones cerebrales. El equipo interdisciplinar de la unidad está integrado por profesionales de la medicina, enfermería, neuropsicología, logopedia, trabajo social, terapia ocupacional y fisioterapia.

En 1999 Institut Guttmann se constituye como Instituto Universitario de Neurorehabilitación adscrito a la Universitat Autònoma de Barcelona. La confluencia del instituto universitario con el hospital especializado posibilita desarrollar soluciones sostenibles para favorecer mejores alternativas asistenciales, trasladando los resultados de la investigación a la práctica clínica.



FIGURA 1: Institut Guttmann (Barcelona). Situado en el antiguo Hospital de la Lluita Antivenèria.

El Institut Guttmann se ubica en el barrio barcelonés de La Sagrera, en el edificio en desuso del Hospital de la Lluita Antivenèria², cedido en usufructo a la Asociación Nacional de Inválidos Civiles (ver figura 1). En sus primeros compases, ocupa la planta baja del antiguo hospital: las dos plantas superiores albergan a los damnificados por las inundaciones del Vallés del año 1962. A mediados de 1966 el instituto comprende planta baja y primera planta;

² El Hospital de la Lluita Antivenèria, constituido en 1931, es un sanatorio destinado a enfermedades venéreas ubicado en las instalaciones del antiguo Hospital de la Magdalena (construido en 1923).



FIGURA 2: Instalaciones del Hospital de Neurorehabilitación Institut Guttmann (Badalona).

El 11 de mayo de 2002 Institut Guttmann se traslada a Badalona, ciudad próxima a Barcelona (ver figura 2). Las nuevas instalaciones permiten aumentar su capacidad asistencial: 152 camas distribuidas en cuatro unidades de hospitalización, 70 plazas de hospital de día y 40 de rehabilitación infantil ambulatoria en horario extraescolar (Escofet, 2002). Actualmente, Institut Guttmann es un hospital incluido en el Servicio Nacional de Salud Español y acreditado

como hospital de referencia por el Departamento de Salud de la Generalitat de Catalunya.

Históricamente, Institut Guttmann se ha caracterizado por un alto grado de compromiso social y colaboración con las asociaciones que representan a las personas con discapacidad. Este posicionamiento ideológico conlleva que, paralelamente a las actividades hospitalarias y científicas, sus profesionales desarrollen acciones de carácter social en los ámbitos de la prevención, la divulgación y la sensibilización social.

UNIDAD DE NEUROPSICOLOGÍA: SINOPSIS HISTÓRICA

A principios de la década de 1980, la mejora del tratamiento médico-quirúrgico proporcionado en el territorio español comporta un incremento sustancial del número de personas que sobreviven tras sufrir un traumatismo craneoencefálico o un ictus; muchos de ellos con graves déficits neurológicos que limitan su capacidad funcional. En este escenario, Institut Guttmann comienza a proporcionar tratamiento rehabilitador a personas con patologías del sistema nervioso central. Uno de los primeros retos es ayudar a aquellas que presentan alteraciones del lenguaje derivadas de un ictus (Sarrias, 1985); de tal forma, se integra en el equipo, a tiempo parcial, Carmina Comerma (logopeda / fonoaudióloga)³. Conscientes de que las personas con lesiones cerebrales pueden presentar una amplia variedad de déficits cognitivos, contactan con Carme Junqué Plaja, neuropsicóloga adjunta del Servicio de Neurología del Hospital de la Santa Creu i Sant Pau (Barcelona), para realizar exploraciones diagnósticas.

En 1983 se constituye la Unidad de Neuropsicología, integrada en el Departamento Psico-social (Institut Guttmann, 2003). La persona responsable de su puesta en marcha es Teresa Roig Rovira, licenciada en psicología y diplomada en logopedia (ver figura 3). Roig Rovira se forma en neuropsicología junto al Dr. Jordi Peña-Casanova, neurólogo del Hospital del Mar (Barcelona) y discípulo del Dr. Lluís Barraquer-Bordas, pionero de la neuropsicología española (García-Molina & Roig-Rovira, 2015). Antes de unirse a la plantilla de Institut Guttmann, Roig Rovira trabaja como psicóloga asistente del servicio de neuropsicología del Hospital

de Mar, lugar en el que coincide con Carmina Comerma. Ella le explica que en Institut Guttmann necesitan un neuropsicólogo para realizar tratamientos rehabilitadores en pacientes con lesiones cerebrales. Se incorpora como neuropsicóloga dos tardes a la semana; tras la jubilación de Comerma, también ejerce en calidad de logopeda. Roig Rovira ocupa el cargo de responsable de la Unidad de Neuropsicología hasta su jubilación, en abril de 2015.

La Unidad de Neuropsicología tiene como objetivo proporcionar tratamiento rehabilitador a las personas con lesiones cerebrales ingresadas en Institut Guttmann, así como a los que acuden en régimen de hospital de día. Partiendo de modelos holísticos, como los de Ben-Yishay, Prigatano o Christensen, el programa de rehabilitación neuropsicológica implementado en Institut Guttmann considera la globalidad de la persona, incluyendo tanto la atención a los aspectos cognitivos, como a los conductuales, emocionales y psicosociales. Otro aspecto destacable, es la integración de la familia en el proceso asistencial. La intervención familiar se articula a través de la educación, el apoyo emocional y el tratamiento de problemas específicos.



FIGURA 3: Miembros del equipo asistencial del Institut Guttmann (c. 1989). Primera fila (sentados, de izquierda a derecha): Josep Bagunyà (neurólogo), Lluïsa Curcoll (psicóloga), Ana M. Pérez (farmacéutica), Domingo Guevara (médico rehabilitador), Lourdes Aloy (médico rehabilitador), Fabián Sarrias (urólogo). Segunda fila (de pie, de izquierda a derecha): **Teresa Roig** (neuropsicóloga), José Luís Córdoba (médico rehabilitador), Josep María Ramírez (médico), Albert Borau (urólogo), Miquel Sarrias (cirujano ortopédico; director médico de la institución entre 1965 y 1997), Xavier Curia (médico internista), José

3 En 1962 Carmina Comerma inicia su actividad profesional como logopeda en el Hospital de la Santa Creu i Sant Pau. Posteriormente trabaja en el Servicio de Neuropsiquiatría del Hospital del Mar y en el Centro Municipal Fonoaudiológico de Barcelona.

Manuel Romacho (psiquiatra), Josep Guardia (médico de empresa), Joan Vidal (médico rehabilitador). Tercera fila (de pie, de izquierda a derecha): Genís Buendía (administrador), Joan Fontseré (administrativo), Joan Gispert (farmacéutico).

En la España de mediados de la década de 1980 no existe un tejido asociativo que proporcione ayuda y orientación a las personas afectadas por una lesión cerebral y sus familias (Harvey & Roig, 1987). El 27 de mayo de 1988 se constituye, en Barcelona, la Asociación de Traumatizados Cráneo Encefálicos (TRACE) (Harvey & Roig, 1988). Esta experiencia, pionera del movimiento asociativo español vinculado con el daño cerebral, es promovido por el Departamento Psico-social de Institut Guttmann.

A finales de la década de 1980, Roig Rovira constata la necesidad de poder continuar la rehabilitación neuropsicológica tras el alta hospitalaria. A tal efecto, en 1989 se crea la Unidad de Rehabilitación de Funciones Superiores. Ésta atiende tanto a pacientes procedentes de Institut Guttmann como de otros centros hospitalarios que no disponen de un servicio de neuropsicológica.

La demanda de tratamiento neuropsicológico aumenta a mediados de la década de 1990, haciendo necesario incorporar profesionales a la Unidad de Neuropsicología. En 1995 se une Antonia Enseñat Cantallops (neuropsicóloga)⁴, en 1997 Montserrat Martinell Gispert-Sauch (logopeda). Actualmente la plantilla de la unidad está formada por seis neuropsicólogos, cinco logopedas y una musicoterapeuta.

En el curso académico 1988-89, gracias a un convenio con la Unidad Docente del Hospital de Mar, la Unidad de Neuropsicología de Institut Guttmann deviene centro de prácticas del Máster en Neuropsicología dirigido por el Dr. Peña-Casanova. En el curso 2001-02 Institut Guttmann, como Instituto Universitario adscrito a la Universitat Autònoma de Barcelona, imparte un curso de especialización en neuropsicología; en el bienio 2003-04 amplía la formación con un curso de especialización en logopedia y neurorehabilitación. En el curso 2010-11 se pone en funcionamiento el Máster Universitario en Rehabilitación Neuropsicológica y Estimulación Cognitiva, dirigido por la Dra. Roig Rovira.

En 1988 Institut Guttmann crea una unidad de neurorehabilitación infanto-juvenil para menores con lesiones

cerebrales adquiridas o congénitas. El equipo de trabajo multidisciplinar está formado por diferentes profesionales: médico rehabilitador, enfermera, fisioterapeuta, terapeuta ocupacional, neuropsicólogo, psicólogo, logopeda, trabajador social y técnico ortopédico. Enseñat Cantallops coordina el área de neuropsicológica infanto-juvenil desde 1998. El modelo de rehabilitación neuropsicológica pediátrica incluye programas educativos dirigidos a familias y escuelas (Enseñat et al., 2015).

REHABILITACIÓN NEUROPSICOLÓGICA:

MARCO DE TRABAJO

El programa de rehabilitación neuropsicológica de Institut Guttmann parte de una visión holística de la persona. Sus objetivos son: (1) favorecer su estabilidad conductual; (2) promover la recuperación de procesos cognitivos alterados; (3) mejorar su capacidad funcional, pese a la existencia de déficits subyacentes; (4) facilitar su ajuste emocional a los cambios generados por las lesiones neurológicas; y (5) asistirle, y acompañarla, en su tránsito hacia una nueva identidad.

Los pacientes atendidos en este programa se encuentran en una fase subaguda post-lesional y presentan alteraciones neuropsicológicas originadas, fundamentalmente, por un traumatismo craneoencefálico o un ictus (de tipo isquémico o hemorrágico). Algunos de ellos están ingresados en una de las unidades de hospitalización del centro, mientras que otros acuden de forma ambulatoria (hospital de día). El tiempo medio de tratamiento se sitúa alrededor de los seis meses; su intensidad y objetivos vienen determinados por las necesidades, y perfil neuropsicológico, del paciente.

El modelo integral de rehabilitación neuropsicológica de la Unidad de Neuropsicología de Institut Guttmann (ver figura 4) comprende cuatro ámbitos: cognición, conducta, emoción e identidad. Más allá de la persona afectada, también proporciona asistencia a sus familiares y allegados (afectados indirectos). Así, el programa rehabilitador incorpora herramientas de rehabilitación cognitiva, técnicas de modificación de conducta, neuropsicoterapia e intervención en el medio familiar.

El programa de rehabilitación está precedido por una evaluación neuropsicológica que permite detectar, describir y cuantificar las posibles alteraciones, fijar los objetivos terapéuticos y diseñar un plan de trabajo acorde a las necesidades del paciente (Bernabéu & Roig, 1999). La evaluación actúa como un mapa de navegación: indicándonos donde

4 Antonia Enseñat Cantallops asume la dirección de la Unidad de Neuropsicología en 2016.

estamos (caracterización del paciente), a dónde vamos (objetivos) y cómo llegaremos (intervenciones).

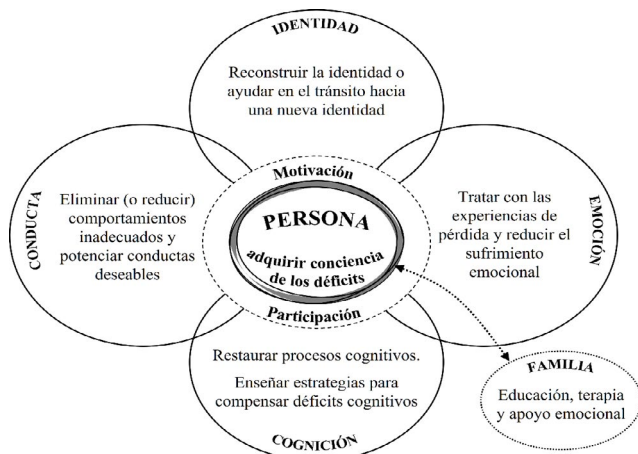


FIGURA 4: Modelo integral de rehabilitación neuropsicológica de la Unidad de Neuropsicología de Institut Guttmann.

La **rehabilitación cognitiva** tiene como objetivo optimizar la recuperación, comprender mejor la naturaleza de las alteraciones y desarrollar estrategias que permitan compensarlas. Las técnicas de rehabilitación cognitiva empleadas se agrupan, básicamente, en dos categorías: técnicas restitutivas y estrategias compensatorias.

Las técnicas restitutivas persiguen reducir el déficit mejorando la función a través del tratamiento directo de los déficits ejecutivos subyacentes: recuperar la función en sí misma, es decir, alcanzar los objetivos deseados empleando los mismos medios (procesos cognitivos) utilizados antes de la lesión. Esta estrategia terapéutica parte de la base de que se estimulan y mejoran las capacidades cognitivas alteradas mediante el ejercicio y la práctica repetitiva de tareas administradas en soporte analógico o digital. En la Unidad de Neuropsicología el soporte utilizado, desde mediados de la década de del 2000, es Guttmann, NeuroPersonalTrainer® (Solana et al., 2014; Solana et al., 2015). Esta plataforma de telerehabilitación, producto de la investigación traslacional desarrollada en Institut Guttmann, permite una rehabilitación cognitiva intensiva, personalizada y supervisada.

Las estrategias compensatorias buscan minimizar las limitaciones funcionales, enseñando o entrenando a la persona a utilizar procedimientos alternativos con el fin de evitar las dificultades que experimenta como consecuencia de los déficits cognitivos. En este caso, en lugar de favorecer

la recuperación de los medios (procesos cognitivos) utilizados antes de la lesión, buscamos favorecer la recuperación de objetivos: lo relevante es lograr unos objetivos determinados, independientemente de los medios empleados a tal efecto (medios que, con toda probabilidad, serán diferentes a los utilizados antes de la lesión). Nos centramos en enseñar o entrenar a la persona a utilizar estrategias alternativas o ayudas externas que le permitan llevar a cabo las actividades de la vida diaria, y de esta manera evitar las dificultades que puedan surgir como consecuencia de los déficits cognitivos. La utilización de ayudas externas incrementa la sensación de autonomía y favorece la autoestima de la persona. Si bien en un primer momento algunos pacientes son reticentes a utilizarlas, es importante transmitir la idea de que gracias a ellas mejorarán sustancialmente su capacidad funcional.

En los primeros compases de la rehabilitación cognitiva, pocos días o semanas después de la lesión, habitualmente intentamos restaurar las funciones perdidas o mermadas. Transcurrido un tiempo, si la restauración de la función no es factible, introducimos el uso de estrategias compensatorias. Si bien la restauración de la función (o al menos su restauración parcial) puede ocurrir años después de la lesión, en la mayoría de los casos cuando las técnicas restitutivas no son útiles la alternativa de elección es el entrenamiento en estrategias compensatorias. Pese al escenario descrito en las líneas anteriores, técnicas restitutivas y estrategias compensatorias no son mutuamente excluyentes, pudiéndose combinar a lo largo del proceso rehabilitador en función de las necesidades, habilidades y capacidades del paciente.

La naturaleza y gravedad de los déficits cognitivos influyen decisivamente en el tipo de abordaje terapéutico adoptado. Las personas que son incapaces de guiar su conducta de forma autónoma, y que no son conscientes de los déficits que presentan, acostumbran a beneficiarse de tratamientos basados en la modificación del entorno y el entrenamiento en rutinas. El entrenamiento en estrategias compensatorias y/o la aplicación de técnicas restauradoras suele ser más efectiva en aquellas que tienen una mayor capacidad de iniciativa y autorregulación.

Tal y como se ha señalado en el párrafo anterior, el nivel de conciencia que la persona tiene de sus déficits cognitivos, así como de las limitaciones funcionales que comportan⁵,

⁵ La falta de conciencia de déficits (también conocida como anosognosia)

es clave en el éxito o fracaso de la rehabilitación. El nivel de participación e implicación es muy limitado (sino nulo) cuando no percibe que sus capacidades cognitivas están mermadas. En esta situación, enseñarle estrategias compensatorias, o bien realizar actividades con el fin de mejorar una capacidad cognitiva concreta, resulta poco apropiado. Cuando toma conciencia de los déficits que presenta, así como de las implicaciones que éstas tienen para su vida diaria, el nivel de motivación e implicación en el proceso rehabilitador aumenta considerablemente. En estos casos el entrenamiento en estrategias compensatorias está especialmente indicado.

Durante muchos años se han equiparado los términos rehabilitación cognitiva y rehabilitación neuropsicológica, considerando que son sinónimos. Esta visión, eminentemente cognitivo-céntrica, considera que el único objetivo de la rehabilitación neuropsicológica es la mejora del funcionamiento cognitivo. Lejos de estos planteamientos conceptuales, el programa de rehabilitación neuropsicológica de Institut Guttmann también aborda otras alteraciones asociadas a lesiones cerebrales, como las comportamentales, emocionales o identitarias.

Alteraciones comportamentales como la irritabilidad, la agresividad, la desinhibición o el egocentrismo condicionan la capacidad de participación de la persona en el programa rehabilitador, generan malestar en las familias y tensión en los profesionales. Las **intervenciones conductuales** son esenciales para eliminar o reducir comportamientos inadecuados y potenciar conductas deseables. Con este objetivo, utilizamos abordajes no-farmacológicos, normalmente técnicas de modificación de conducta (Mimentza & Quemada, 2011). Estas técnicas tienen en común el análisis y la manipulación de la asociación entre los estímulos y las respuestas de las personas, e incluyen las consecuencias de estas en forma de estímulos reforzantes o aversivos, con el objetivo de aumentar las conductas deseables y eliminar las no deseadas.

Toda patología cerebral es un proceso psicológico único, con profundas implicaciones emocionales. Con frecuencia el proceso de recuperación no implica necesariamente volver al estado pre-mórbido, sino adaptarse a una nueva realidad.

es un fenómeno clínico en el que el paciente no parece ser consciente de sus déficits neurológico y/o neuropsicológicos; déficits que sí son evidentes para los demás (profesionales y familiares).

En este proceso de adaptación, la **neuropsicoterapia** ayuda a reducir el sufrimiento psicológico/emocional, promover una actitud activa de compromiso con la vida tal y como es tras la lesión y restablecer un sentido de propósito o significado a la vida (García-Molina et al., 2014). Este abordaje terapéutico requiere, inexcusablemente, incorporar las necesidades, circunstancias y capacidades de la persona. Sin olvidar la importancia de sus experiencias previas, personalidad premórbida o condiciones personales actuales. Todo ello conforma una compleja constelación de variables que hacen que cada paciente sea único y diferente. Para tratar adecuadamente a una persona con una lesión cerebral necesitamos, tal y como refiere Prigatano, saber cómo veía la vida en el pasado, cómo se enfrenta a la adversidad y qué creencias culturales o religiosas han influido en la forma en que ha elegido vivir la vida (Prigatano, 1999; Prigatano, 2019).

En párrafos anteriores se ha subrayado la importancia del nivel de conciencia de los déficits en el proceso rehabilitador. En el momento que la persona desarrolla una mayor conciencia de su situación (y de los déficits derivados de la lesión), y se ve confrontado con sus dificultades para retomar roles familiares, sociales y laborales, también puede ser más consciente del impacto del daño cerebral sobre su identidad. Nuestra labor es asistirle en la reconstrucción de su identidad, a partir del reconocimiento y comprensión de sus nuevas posibilidades y capacidades personales. Sin perder de vista que no siempre es posible restituir la identidad original. Aquellas personas que son capaces de formar un sentido de sí mismos realista tienen más probabilidades de experimentar un ajuste post-lesional positivo.

Toda persona busca, según Ylvisaker, un significado y un propósito vital (Ylvisaker et al., 2007). Con frecuencia nuestro sentido existencial gira en torno a la productividad (entendida como la sensación de utilidad; esté o no vinculada a una remuneración económica) y las relaciones personales (que proporcionan sensación de pertenencia a un colectivo). Tras una lesión cerebral las metas y actividades que definían el significado vital pre-lesional pueden percibirse como quimeras inaccesibles. Como parte del modelo integral de rehabilitación neuropsicológica de la Unidad de Neuropsicología, ayudamos a la persona a identificar nuevos objetivos: el ser humano no anhela vivir sin tensión, sino esforzarse y luchar por una meta que merezca la pena. Vivir requiere objetivos existenciales que comporten dirigir nuestras acciones y esfuerzos hacia lo que queremos lograr; tanto en el ámbito familiar, como en el

social o laboral. El filósofo alemán Friedrich Nietzsche escribe en su obra *El ocaso de los ídolos* (1887): "Quien tiene un porqué para vivir, encontrará casi siempre el cómo".

Es innegable que el paciente es el actor principal de la rehabilitación neuropsicológica, pero la familia también desempeña un papel destacado. Papel que ejerce en dos dimensiones: como agente receptor de tratamiento y como agente emisor de tratamiento o facilitador del proceso rehabilitador. Contar con los familiares como agentes involucrados en el proceso rehabilitador resulta imprescindible para garantizar el éxito de la intervención. Comparten muchas horas con el paciente, situándose en una posición excepcional para fomentar el uso de estrategias compensatorias o actuar como control externo; así como para favorecer la generalización de los aprendizajes adquiridos en las sesiones de rehabilitación.

Ninguna familia está preparada para hacer frente a las consecuencias de una lesión cerebral. Cuando ésta irrumpe genera una crisis, modificando las relaciones entre sus miembros y alterando las expectativas y objetivos de la unidad familiar. Las lesiones cerebrales afectan profundamente las relaciones familiares, socavando la capacidad de adaptación y ajuste, tanto del afectado como de sus allegados (Bruna et al, 2011). Hay que subrayar que el impacto de la situación es diferente según la estructura del sistema familiar, al tiempo que es heterogéneo para cada uno de sus miembros. Asimismo, la respuesta familiar varía en función del momento evolutivo y los déficits que presenta el paciente. La familia, al igual que la persona afectada, también evoluciona a lo largo del proceso de recuperación, experimentando cambios en sus preocupaciones, anhelos o miedos.

La **intervención en el medio familiar** tiene como objetivos: (1) proporcionar información sobre el daño cerebral, (2) adquirir i desarrollar habilidades útiles para afrontar las secuelas derivadas de las lesiones cerebrales, (3) aprender a tratar adecuadamente al paciente, (4) aprender estrategias de afrontamiento para problemas particulares (p.ej. episodios de agresividad o irritabilidad), (5) proporcionar apoyo emocional y (6) preparar a la familia para el regreso al domicilio (muchas veces en un contexto en el que el paciente continua presentando alteraciones cognitivas, conductuales y emocionales).

EPÍLOGO

En enero de 2019 se inaugura Guttman Barcelona, Instituto de Salud Cerebral y neurorehabilitación. El nuevo complejo

asistencial, ubicado en los terrenos que ocupaba Institut Guttmann en Barcelona, ofrece tratamiento a personas con lesiones medulares o daño cerebral, así como a otras patologías que puedan beneficiarse de su conocimiento y experiencia en neurorehabilitación. La actividad del centro se organiza en clínicas: Clínica del neurodesarrollo, Clínica del ictus y del daño cerebral adquirido, Clínica del Parkinson y otros trastornos del movimiento o Clínica de la Salud Cerebral, entre otras. El equipo transdisciplinar está formado por profesionales de diversos ámbitos de la rehabilitación, entre ellos neuropsicólogas y logopedas.

La Unidad de Neuropsicología de Institut Guttmann ha crecido, evolucionado y cambiado sustancialmente desde su creación en el año 1983. Uno de los cambios más significativos es la sustitución, a principios del siglo XXI, de los tradicionales ejercicios de *papel y lápiz* por tareas informatizadas, que permiten ofrecer tratamientos más personalizados, lúdicos, dinámicos y controlados. No obstante, la misión de la Unidad de Neuropsicología ha permanecido inalterable en sus cuatro décadas de vida: ayudar a las personas con patologías neurológicas, así como a sus familias, a mejorar su calidad de vida.

REFERENCIAS

- Bernabéu, M., & Roig, T. (1999). *La rehabilitación del traumatismo craneoencefálico: un enfoque interdisciplinar*. Fundació Institut Guttmann.
- Bruna, O., Junqué, C., Pérez, C., Mataró, M., Subirana, J., Aramburu, I., & Macias, C. (2011). La familia en el proceso de rehabilitación neuropsicológica. En O. Bruna, T. Roig, M. Puyuelo, C. Junqué, & A. Ruano (Eds.), *Rehabilitación neuropsicológica: Intervención y práctica clínica*. (pp. 397-415). Elsevier Masson.
- Enseñat, A., García-Molina, A., & Roig, T. (2015). *Neuropsicología Pediátrica*. Editorial Síntesis.
- Escofet, J.M. (2002). *Presentación del nuevo Institut Guttmann*. Sobre Ruedas, 52, 2-5
- García-Molina, A., Roig-Rovira, T., Enseñat-Cantalops, A., & Sánchez-Carrión, R. (2014). *Neuropsicoterapia en la rehabilitación del daño cerebral*. Revista de Neurología, 58(3), 125-132.
- García-Molina, A., & Roig-Rovira, T. (2015). *Lluís Barraquer Bordas (1923-2010): precursor de la neuropsicología catalana*. Neurosciences and History, 3(1), 42-44.
- García-Molina, A., & Enseñat-Cantalops, A. (2019). *La rehabilitación neuropsicológica en el siglo XX*. Revista de Neurología, 69(9), 383-391. <https://doi.org/10.33588/rn.6909.2019247>
- García-Molina, A., & Peña-Casanova, J. (2022). *Fundamentos históricos de la neuropsicología y la neurología de la conducta*. Test Barcelona Services.
- Harvey, L., & Roig, M.T. (1987). *Coloquio Europeo sobre la familia del traumatizado cráneo encefálico (TCE)*. Sobre Ruedas, 13, 8-10.
- Harvey, L., & Roig, M.T. (1988). *TRACE (Asociación de Traumatizados Cráneo Encefálicos) ya es una realidad*. Sobre Ruedas, 14, 23.
- Institut Guttmann. (2003). *Entrevista amb: Teresa Roig Rovira*. Butlletí Intern Fundació Institut Guttmann. Fulls informatius, 40.
- Mimentza, N., Quemada, J.I. (2011). Tratamiento de los trastornos emocionales y de la conducta en pacientes con daño cerebral. En O. Bruna, T. Roig, M. Puyuelo, C. Junqué, & A. Ruano (Eds.), *Rehabilitación neuropsicológica: Intervención y práctica clínica*. (pp. 245-256). Elsevier Masson.
- Nybo, T., & Hokkanen, L. (2003). *A brief history of neuropsychology in Finland*. Svensk Neuropsykologi, 3-4, 42-43.
- Prigatano, G.P. (1999). *Principles of Neuropsychological Rehabilitation*. Oxford University Press.
- Prigatano, G.P. (2019). *Clinical Neuropsychology and the Psychological Care of Persons with Brain Disorders*. Oxford University Press.
- Sarrias, M. (1985). *El Instituto Guttmann y el tratamiento médico-rehabilitador del lesionado medular en el período 1965-1985. Perspectivas de futuro*. Sobre Ruedas, 6-7, 4-10.
- Sarrias, M. (1995). *Desde una perspectiva de 30 años*. Sobre Ruedas, 34, 5-7.
- Sarrias, M., Ramírez, J.M., & Vidal, J. (1998). *The Guttmann Institute of Barcelona*. Spinal Cord, 36(7), 514-519. <https://doi.org/10.1038/sj.sc.3100685>
- Solana, J., Cáceres, C., García-Molina, A., Chausa, P., Opisso, E., Roig-Rovira, T., Menasalvas, E., Tormos-Muñoz, J.M., & Gómez, E.J. (2014). *Intelligent Therapy Assistant (ITA) for cognitive rehabilitation in patients with acquired brain injury*. BMC Medical Informatics and Decision Making, 19, 14, 58. <https://doi.org/10.1186/1472-6947-14-58>
- Solana, J., Cáceres, C., García-Molina, A., Opisso, E., Roig, T., Tormos, J.M., & Gómez, E.J. (2015). *Improving brain injury cognitive rehabilitation by personalized telerehabilitation services: Guttmann neuropsychological trainer*. IEEE Journal of Biomedical and Health Informatics, 19(1), 124-131. <https://doi.org/10.1109/JBHI.2014.2354537>
- Vidal, J., & Bernabéu, M. (2009). *Evolución del tratamiento de la lesión medular y el daño cerebral*. Sobre Ruedas, 71, 10-13.
- Ylvisaker, M., Feeney, T., & Capo, M. (2007). *Long-Term Community Supports for Individuals With Co-Occurring Disabilities After Traumatic Brain Injury: Cost Effectiveness and Project-Based Intervention*. Brain Impairment, 8(03), 276-292. <https://doi.org/10.1375/brim.8.3.276>

ARTÍCULO DE REVISIÓN

SOME NUMBERS WORTH KNOWING

ALGUNOS NÚMEROS RELEVANTES

RUDI COETZER*¹

* Correspondencia:

Rudi.Coetzer@thetdgroup.org

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Este artículo de reflexión trata de explorar cómo los clínicos que trabajan en un mundo cada vez más complejo y orientado a los datos en la prestación de salud, interpretan, analizan, asimilan y difunden los datos numéricos que se encuentran habitualmente. Se sugiere que, en ocasiones, durante este proceso, pueden producirse errores involuntarios de razonamiento clínico y pensamiento crítico. El tema principal que se explora es cómo nosotros, como neuropsicólogos clínicos y parte del razonamiento clínico, comunicamos y procesamos la información, más específicamente los números, en nuestras propias mentes, como moneda de cambio para transmitir nuestras ideas, hallazgos, aprehensión, frustraciones o logros en nuestro respectivo trabajo clínico diario. Se utilizan ejemplos prácticos, basados en la práctica, para reflexionar y plantear preguntas sobre algunos de estos errores hipotéticos que podrían producirse. Los ejemplos de errores de razonamiento clínico y pensamiento crítico que se exploran en el documento incluyen los siguientes: No cuestionar críticamente la objetividad de los datos; una tendencia a la complejidad cuando se comunican los datos o los hallazgos clínicos, cuando la parsimonia podría proporcionar una explicación más transparente; ceguera ante situaciones en las que no hay pruebas para un argumento; la incapacidad de considerar hipótesis alternativas que podrían proporcionar una mejor explicación del fenómeno en cuestión. Se sugieren estrategias prácticas y psicológicamente informadas para evitar o minimizar estos errores. Se espera que este artículo estimule la reflexión y el cuestionamiento sobre un aspecto potencialmente "oculto" de nuestro papel como científicos y profesionales que trabajan en entornos sanitarios complejos, ajetreados y a veces abrumadores.

This reflective paper attempts to explore how clinicians working in an increasingly complex, data-driven world of healthcare provision, interpret, analyse, assimilate, and disseminate commonly encountered numerical data. It is suggested that on occasion during this process, unintentional errors of clinical reasoning and critical thinking may occur. The main theme explored is how we as clinical neuropsychologists, as part of clinical reasoning, communicate and process information, more specifically numbers, in our own minds, as a currency for conveying our ideas, findings, apprehension, frustrations, or achievements in our respective worlds of daily clinical work. Practical, practice-based examples are used to reflect on, and ask questions about some of these hypothetical errors that could potentially occur. The examples of errors of clinical reasoning and critical thinking explored in the paper include the following. A failure to critically question the objectivity of data. A tendency to default to complexity when communicating data or clinical findings, when parsimony could potentially provide a more transparent explanation. A 'blindness' to situations where an absence of evidence for an argument may exist. A failure to consider alternative hypotheses which could provide a better explanation of the phenomena under consideration. Practical, psychologically informed strategies to avoid or minimise these errors are suggested. It is hoped that the paper will stimulate further reflection and questioning about a potentially 'hidden' aspect of our role as scientist-practitioners working in complex, busy, and at times overwhelming, healthcare environments.

¹ The Disabilities Trust, Wakefield, UK. School of Human & Behavioural Science, Bangor University, UK. Faculty of Medicine, Health & Life Science, Swansea University, UK

INTRODUCTION

'Brevity is the soul of numbers'

We need to talk about numbers. Numbers have been around for a long time and its use have recently enjoyed a resurgence during the pandemic. Epidemiologists suddenly became rock stars providing the public their daily 'chart hits' during the pandemic. We need numbers to make sense of things, manage our fears, or uncertainty, and to process information around us. Humans grow wiser by developing a deeper understanding of their experiences, and to achieve this, consciously or subconsciously make use of personal observations, statistics, and numbers (Rowntree, 2018). However, it should be made clear this paper is not about the details of mathematics, statistics, research, or data per se. It is primarily about critical thinking. Critical thinking, using the concept of numbers simply as the medium, rather than the specific topic.

How do numbers 'work'? Numbers confer credibility (perceived or real) to what is being said - after all, numbers are at the heart and soul of science, right? But numbers, or numerical concepts, are also used to process, and very briefly summarise thoughts, feelings, and behaviours. Maybe it is the brevity and perceived credibility of numbers in communicating complex, multi-layered information that is responsible for the at times disproportionate impact and potential to influence of numbers, positively or negatively. Which is exactly the reason why we need to talk about numbers. Hopefully this paper will help us consider the need to briefly pause when presented with (or before conveying an idea ourselves) any narrative with a number and consider a bit more critically what is being conveyed, and what the objective facts are. Not all numbers are equally precise, and some numbers might not even constitute anything numerical.

This intentionally provocative paper attempts to reflect on how we as clinical neuropsychologists and practitioner-scientists can possibly sometimes fall into the trap of disseminating, assimilating, and analysing informal, everyday numerical information in an age of data overload perhaps on occasion a little bit too uncritically. At its heart then this paper is about how we as neuropsychologists use numbers. The points made throughout the paper, consider through examples, the role of clinical reasoning, or critical thinking, and concludes with looking at some errors made in these areas, as well as suggest a few strategies to

avoid errors. These errors of clinical reasoning and critical thinking include the failure to question, a preference for complexity when parsimony would provide a more transparent explanation, blindness to an absence of evidence, and not considering alternative hypotheses which could provide a better explanation of the phenomena being considered. It is hoped that the paper will stimulate debate, about how to be a little bit more questioning about how we think about numbers. More specifically, how we as clinical neuropsychologists, communicate and process information, in this case numbers, in our own minds, as a currency for conveying ideas, concerns, frustrations, or achievements in the world of daily clinical work, whilst avoiding making unintentional errors.

CRITICAL THINKING

'Is that a number I see before me?'

There is something mind boggling about numbers. On the one hand seemingly simple, on the other, deceptively complex. Imagine the cognitive leap the first human who counted something, maybe animals, must have made. Why are numbers so complex? Do they always accurately summarise what is being communicated by them - a measurable value? Let's use a hypothetical example from the clinical world of neuropsychology to take a closer look at what is meant here. A consultant neuropsychologist new to the role of consultant tells the supervisor that 'several things are wrong' in the unit or ward where he or she works. How many is 'several', and what is the impact of each? Maybe 7, perhaps 13, or maybe 2. 'Several' sounds like a number of course but isn't one (or even 1!).

Are there possible practical implications from the above example? Well, yes, the first question might be something along the lines of how many things are 'right'? From a clinician-academic perspective, think of a literature review or meta-analysis, the effect risk of bias can have on the result (findings and conclusions). Similarly, from a clinical leadership point of view, behaviourism still holds some utility, or at least explains some of the variance of patients' outcomes. One of the simple 'mantras' from behavioural approaches to change is 'If you want to increase desirable behaviour, reinforce what is working'. And in the context of this paper, we would want to add 'And measure it'. By employing useful numbers, numbers worth knowing. Numbers that tell us what a clinician, clinical team, or organisation, is doing, how often (frequency), for how

long (duration), and even more importantly, what measurable outcomes these activities are achieving for patients.

Most neuropsychologists reading this paper by now would have undoubtedly recognised, is an unashamed reference to the landmark paper by the late Kevin Walsh, 'Some gnomes worth knowing' (Walsh, 1992). If there is one paper all neuropsychologists should read... In fact, this statement should include 're-read'. Since Walsh's seminal paper was published during the early 1990s, the use of data in managed healthcare and evidence-based practice has expanded so rapidly that numbers are now all around us. It doesn't matter if you work in private healthcare, state hospitals, or charitable health and social care providers, numbers increasingly underpin the management and clinical leadership in these organisations, including providers of neuropsychological rehabilitation. Let's now continue our journey to look at the often-hidden implications of automatically accepting all numbers at face value as clinicians, clinical leaders, and clinician-academics.

Here's our first example of well-intended, but most likely (at least in some situations) somewhat meaningless numbers: Psychotherapy sessions are fairly universally thought of as 60 minutes long - 'the therapeutic hour'. Why 60? Why not 45, 30, or 70? Where exactly in this number (60) is the patient considered? In an acute ward 60 minutes is almost always way too lengthy, whereas in post-acute outpatient neuropsychology follow-up clinics 60 minutes is often too little. Perhaps the 'therapeutic hour' is probably more tradition and convention, rather than an actual evidence-based number, or at least in neurorehabilitation settings? What is more important to consider in these settings, is to adapt session time to patients' needs, and more specifically to factors such as vulnerability to fatigue, problems with information processing, and poor working memory, among others (Coetzer, 2013; Judd & Wilson). Another example of how patient needs should dictate session time, would be the wise use of session frequency when working in slow stream rehabilitation, where low frequency of sessions is more likely to be the model of care, than the high session frequency immediately post-acute. Patient need rather than an odd number should inform care.

'IS THERE LUCK IN ODD NUMBERS?'

Some numbers are at best strange, and consequentially difficult to understand from within a clinical reasoning framework. When a number appears to have been arbitrarily

chosen or hoped to accurately represent 'the best guess', it becomes difficult to determine its purpose. Here is a somewhat odd number loved and loathed in equal measures, depending on if one is a purchaser, or provider of managed healthcare. For example, we are often presented with a statement of 'fact' which states that a block of 12 sessions of cognitive behaviour therapy (CBT) is what this service always provides, or should be offering, to all patients. In this case, is there possibly a confusion between research trial design and data, with everyday clinical practice? Or is the predetermined number of sessions simply financially driven? There is huge variance between patients, as determined by their actual clinical needs, and where they are in their rehabilitation journey. For example, there is evidence that early rehabilitation, at a higher intensity, do positively affect patients' outcome after brain injury (E.g., Shiel, Burn, Henry et al, 2002).

Another common number that is often misunderstood, or more precisely, misinterpreted, is cut (-off) scores, especially in the context of self-report questionnaires. For example, it is stated that a patient scored 7 on a questionnaire for depression, where the cut score is 5. based on the score alone the interpretation is made that the patient is significantly depressed. Is that true? Well, he or she may be, but it depends on several factors. Can we be sure of the validity or reliability of the responses of a patient with a traumatic brain injury, where there may be working memory difficulties and impairment of executive functions? For example, the patient may repeat exactly the same response to all items of a test, as a result of poor memory, perseveration, or impulsivity. Or maybe the patient has poor self-awareness. Furthermore, a few of the listed ICD or DSM diagnostic criteria for depression overlap with the core impairments stemming from traumatic brain injury (Coetzer, 2010), for example poor concentration, insomnia, or loss of appetite (sometimes due to anosmia). What exactly explains the patient's numerical score?

Interestingly, when self-report questionnaire data are contrasted with neuropsychological test data, the differences in subjective vs. objective numbers can for some be significant. For example, in a study by Bowler, Adams, Schwarzer and colleagues (2017) comparing participants' self-reported memory problems, found that the association with neuropsychological test data was not always straight forward, and that there was not a perfect correlation between self-reported memory problems and memory test results. Clearly,

the interpretation of numbers, including cut scores, derived from individuals' self-report, is complex. However, are the results any better when rather than individuals participating in research, experts pool their views or answers to questions? Below follows a hypothetical example to consider the complexities of these expert panel generated numbers.

An expert working party tasked with improving clinical care in stroke services after considering all members' views, publish their consensus report. One of the (numerous) recommendations is that there should be 2 neuropsychologists for every ward of 20 or more hospital beds. This seems like a credible recommendation, and most neuropsychologists would hopefully be delighted to embrace this conclusion. But wait, there is a number missing! Will there be funding attached to providing these 2 posts? And, while we are on the number 2, does it capture the whole truth of what's required in this clinical environment? Maybe, but it will depend on what these 2 neuropsychologists do on a day-to-day basis. Providing direct patient care, yes, the mathematics show that each can cover 10 beds over a 5-day rolling period. Doing primarily non-direct patient work, it is difficult to understand the numbers and value added, never mind outcomes for patients.

Related to the above example, there is a potentially hidden suspect, which is about the number 1. Philosophically 1 almost isn't a number, as it doesn't really count anything. The number 1 metaphorically speaking has two main friends, binary maths, and nominal (or categorical) data in statistics (Chi square). To return to the above example, if a neuropsychologist works from a standpoint of 'one patient seen perfectly = perfection of clinical practice', this can have a profound impact on throughput. How lucky must the number 1 be for the neuropsychologist in this case - only 1 patient to see, with the added luxury of lots of time to do more than what is needed! However, epidemiology - and the neuropsychologist's poor colleagues picking up the rest of the referrals or waiting list - will almost certainly disagree with this way of thinking about typical case numbers per clinician. Not to mention the hospital manager responsible for performance and patient throughput. But if still in doubt, think about, and reflect on what is captured in statistics by averages, medians, standard deviations, and outliers, and why this matter.

'THINKING (ABOUT NUMBERS) IS FREE'

A neuropsychologist is asked to assess a patient who is reported to have suffered a traumatic brain injury following an accident at work. The neuropsychologist is told by the

employer that the patient was unconscious for 3 months and is now, 7 months after the injury, ready to return to full-time work. While this may be possible, it is perhaps unlikely based on what we know about a fairly large body of research about markers of severity and early outcome after traumatic brain injury. For example, Ruet, Jourdan, Bayen et al (2018) found that there is a significant association between numerical clinical markers of increased injury severity and poor employment outcome after traumatic brain injury. Crucial here is to confirm the length of period of loss of consciousness, by for example reading the patient's hospital medical notes. Narrative remains narrative (subjective) irrespective of the number (s) quoted therein, until data confirms it as objective, meaning and actual number(s). Thinking about and considering what the precise numbers are in each case, costs nothing, and is good practice to ensure the best care for patients.

Is there strength in numbers? More specifically, group thinking. This depends on the size of the group, or statistically speaking the N, or sample size, one of the cornerstones of increasing confidence of findings. For the purpose of providing an example, let's say a small group (say about 10, or the approximate size of a jury) consider appeals after rejected applications for disability support. After debating the case, the majority (say 8) agree that the applicant (a patient of a neuropsychologist) sustained a severe traumatic brain injury, but also conclude that the person is fit for work and therefore only entitled to a 30% payment of a medical pension, or state disability allowance. A fundamental question here is how likely it is that a sample size of 10 people not posing any specialist knowledge about traumatic brain injury would be large enough to achieve statistical significance (or confidence) to ensure that their conclusion is numerically accurate? Neuropsychologists have a professional duty to advocate for their patients, and present factual data (numbers) representing the severity of their injury and disability, to prevent our patients from receiving compensation, state support or judgements potentially based on opinion, as opposed to objective data.

'UNEASY LIES THE NUMBER THAT WEARS A CROWN'

For clinicians and clinical academics, some of the more tricky numbers to understand are those received from senior management, for example contained in corporate policies. Take this hypothetical example to illustrate the point. A healthcare organisation caring for neurological

patients decides that every new admission should have a set of 5 questionnaires and screening instruments administered, before concluding the assessment with a standardised neuropsychological battery consisting of a battery of 7 tests. This rigid approach to produce a predetermined dataset of numbers assume that there are no differences between individual patients and their respective impairments, never mind the differences between the clinical profiles of traumatic brain injury, stroke, brain infections and so forth. Now add demographics such as patients' age, pre-morbid education, time since injury and injury severity, and the fixed number of assessments approach just doesn't add up anymore. Indeed, the deductive hypothesis testing approach (see e.g. Larabee, 2012, for a description) in neuropsychology posits that individualised assessment (and per implication, rehabilitation) is possibly 'king'.

Similarly, take the following scenario where a neuropsychologist is the senior member of a multi-disciplinary team. For the sake of the example, say that the average length of training as a neuropsychologist is between 8 and 10 years. Furthermore, for the sake of this hypothetical example, there are 10 hours of lectures or academic assignments per week (it is likely much higher), for 8 of the 12 months per year (4 months are holidays). The end result of this extended and comprehensive training is an integration of complex, unique skills and knowledge. Now, the multi-disciplinary team all see patients as a core component of their professional practice. Except the neuropsychologist, who spends the majority of his or her time, providing supervision or training to others, so that they can do...

... the tasks the neuropsychologist can, by virtue of their training almost certainly perform more effectively.

Of course, there is absolutely a place for supporting other professions to develop basic neuropsychology skills, but perhaps not as one of the main components of a frontline clinician's role. The numbers just don't add up. If we dispassionately consider the numbers (training hours, cost to the state or universities, etc.) of the average neuropsychologist's training, the neuropsychologist would have to provide an awful lot of supervision and training hours to make up for that investment. Furthermore, swing this argument around, and try to think of the last time a physiotherapist, doctor, or occupational therapist, as a core component of their roles, provided supervision or training to neuropsychologists, for neuropsychologists to perform key aspects of these professions... Perhaps more importantly even than the purely

hypothetical numbers in this example, is the philosophical question a colleague recently asked - if it is indeed so complex and lengthy to train as neuropsychologist, how can these skills and knowledge be transferred so easily within a minuscule fraction of the time required to acquire these skills and knowledge in the first place?

'LISTEN TO MANY, SPEAK ABOUT A FEW'

To have impact, numbers should ideally be simple to understand for anyone, but at the same time not become so diluted that they become totally meaningless. Often numbers summarise large, complex datasets. Like the power of numbers to capture multiple layers of information, similarly Shakespeare's prose is beautiful too in both its complexity, and simplicity. Take for example the lines 'I am as true as truth's simplicity, and simpler than the infancy of truth' (William Shakespeare, *Troilus and Cressida*, 1602). Furthermore, Latin, similar to numbers, also has the power to capture vast meaning. But both though can also sometimes 'hide', rather than 'reveal' what needs to be communicated to certain audiences. Why, when speaking to an audience other than legal professionals, use the term *causal nexus* when instead using 'the most likely cause of this (effect) was...' would make it clear what was being said? Simplicity is probably closer to the truth, or essence of what is being communicated.

Numbers, like Latin, can sometimes also make complex data or concepts impenetrable and nebulous for some audiences. Using numbers wisely has the power to possibly democratise science and facilitate access to some of the complex concepts of clinical neuropsychology. Ideally anyone should be able to understand the fundamental truths of what is being communicated, and what the numbers quoted to evidence these mean. For example, using simple, non-technical language when providing feedback to patients and relatives following neuropsychological assessment, can help ensure that the key messages are understood. The ability to make simple what is complex is a skill that requires 'listening' to a large amount of numerical data, but to 'speak' only about the headlines, or conclusions. A good example of what is meant here, is to look at how outcome reports, or the annual reports of health and social care organisations are written.

Although outcome data generally tend to capture complex numerical information, how these data (or numbers) are communicated should ideally be easy to understand.

Most people know what a percentage is and what it means. For example, rather than report the details of statistical significance, range, confidence intervals, averages, percentiles, z scores, and standard deviations of patients' outcome over a finely graded list of post-rehab destinations, how about '45% of our patients were discharged to less restrictive settings during 2022' as a headline? The former detailed, statistically sound data are for a professional journal, and are excellent for that audience, but need to be made more accessible for reports intended for readers who want to know, in simple terms, what happened to a hospital's patients. Less can sometimes be closer to the truth.

DISCUSSION

'All that glitters is not a number'

Data are the gold of our time. One of the core ideas presented in this paper, was that some 'numbers' are not numbers which are possible to meaningfully measure, or data amenable to objective comparison, but that some numbers we are presented with can rather be seen as adjectives used to convey subjective emotions, thoughts, and perceptions. Neuropsychologists, almost certainly just like other healthcare professionals, perhaps unintentionally or even subconsciously commit errors of clinical reason when we fail to critically appraise numerical data. Numbers and statistics make it possible for us to summarize data, compare findings, make sense of what it means and predict more accurately than we would be able to in our everyday conversations (Rowntree, 2018). This paper intended to highlight common errors and stimulate critical thinking. The skill to question narratives containing numbers can potentially have some benefits for the clinical training of future practitioners, the provision of patient care, and developing clinically informed leadership of healthcare organisations specialising in the care of neurological patients.

The common errors of clinical reasoning and critical thinking throughout the examples presented in this paper included the following. The first is a failure to question (or automatic acceptance of 'facts'). A useful strategy here is almost similar to the classic CBT exercise of finding the evidence (or absence thereof) for thoughts. An even simpler strategy is to use the mantra of always reminding ourselves of what the difference between 'objective' and 'subjective' is. For example, when reading a clinical report or listening to what is being presented, try to think about what is an

unequivocal fact (a Glasgow Coma Score or 7/15 for 3 days in the medical notes), versus narrative ('I was unconscious for a couple of hours'), hearsay evidence ('someone said they saw him walking around after the crash'), or a third party's opinion ('he doesn't have a brain injury, he's just seeking compensation'). The second error in some of the examples is the almost automatic preference for complexity when parsimony could provide a more transparent explanation or facilitate better communication. When explaining something to patients, families, or non-neuropsychologists, stop, pause, and first mentally do the age-old psychotherapy exercise or role reversal. Ask the question, if I were the patient, or a member of a lay audience, truthfully, would I understand the core messages being conveyed to me?

The third common error is the mirror image of the famous quote of 'absence of evidence is not evidence of absence' (unknown): blindness to an absence of evidence. One way to think about how to avoid this error, is perhaps more psychodynamic or psychoanalytic in nature. It is likely that this type of error is made more subconsciously. Being more aware of how emotions effect our decisions may be helpful. The sense that 'something doesn't feel quite right' shouldn't be ignored. If it doesn't feel right, it probably isn't, may be a useful mantra to remember. A more cognitive strategy might be to ask the question, 'if this were to be presented in court to a judge, what will the sentence be?'... The fourth, and final error, was failing to consider alternative hypotheses which could potentially provide a better explanation of the phenomena being considered. As scientist-practitioners, neuropsychologists are well placed to avoid this error by asking themselves if what is being presented as the facts, would be possible to write up as a state-of-the-art literature review for a peer reviewed journal, and what the outcome of the review will be. It is hoped that the outcome of the present paper will be that some of the ideas presented here will stimulate further debate around the role of critical thinking and clinical reasoning to prevent data, the gold of our time, from becoming fool's gold.

REFERENCES

- Bowler, R. M., Adams, S. W., Schwarzer, R., Gocheva, V V, Roels, H A, Kim, Y., Kircos, C. L., Wright, C. W., Colledge, M., Bollweg, G. & Lobdell, D. T. (2017) Validity of self-reported concentration and memory problems: Relationship with neuropsychological assessment and depression, *Journal of Clinical and Experimental Neuropsychology*, 39:10, 1026-1036.
- Coetzer, R. (2010). *Anxiety and mood disorders following Traumatic Brain Injury: Clinical Assessment and Psychotherapy*. Karnak Books, London, UK.
- Coetzer, R (2013). *The role of psychotherapy in brain injury. Chapter 9. In H. Muenchberger, E. Kendall & J Wright. Health and healing after traumatic brain injury*. ABC Clío, Praeger.
- Judd, D. & Wilson, S. L. (2005). Psychotherapy with brain injury survivors: An investigation of the challenges encountered by clinicians and their modifications to therapeutic practice. *Brain Injury*, 19 (6): 437 - 449.
- Larrabee, G. J. (2012). A scientific approach to forensic neuropsychology. In G. J. Larrabee (Ed.), *Forensic neuropsychology: A scientific approach* (pp. 3–22). Oxford University Press.
- Rowntree, D. (2018). *Statistics without tears. An introduction for non-mathematicians*. Penguin Books, UK.
- Ruet, A., Jourdan, C., Bayen, E., Darnoux, E., Sahridj, D., Ghout, I., Azerad, S., Diehl, P. P., Aegerter, P., Charanton, J., Azouvi, C.V., & Azouvi, P. (2018) Employment outcome four years after a severe traumatic brain injury: results of the Paris severe traumatic brain injury study, *Disability and Rehabilitation*, 40:18, 2200-2207.
- Shiel A., Burn, J. P., Henry, D., Clark, J., Wilson, B. A., Burnett, M. E. & McLellan, D. L. (2001). The effects of increased rehabilitation therapy after brain injury: results of a prospective controlled trial. *Clinical Rehabilitation*; 15 (5): 501 - 514.
- Walsh, K. (1992). Some gnomes worth knowing, *Clinical Neuropsychologist*: 6, 2: 119 - 133.

CONOCIENDO LO QUE NO SE VE: UN SCOPING REVIEW SOBRE LESIONES CEREBRALES INVISIBLES Y SU PSICOEDUCACIÓN

KNOWING WHAT IS NOT SEEN: A SCOPING REVIEW ON INVISIBLE BRAIN INJURIES AND THEIR PSYCHOEDUCATION

AITANA GRASSO-CLADERA*¹ & CHRISTIAN SALAS^{1,2}

*** Correspondencia:**

Aitana Grasso-Cladera, Ps
aitana.grasso@mail.udp.cl

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Las Lesiones Cerebrales Adquiridas (LCA) pueden generar una amplia gama de déficits motores/sensoriales, cognitivos, conductuales y socioemocionales, impactando la reinserción comunitaria, salud mental y calidad de vida de los sobrevivientes. Diversos autores, y particularmente sobrevivientes de LCA, han planteado que la visibilidad de los déficits puede ser una variable relevante a considerar, ya que las dificultades invisibles tienden a generar mayores barreras en el proceso de retorno a la comunidad. A pesar del creciente interés en los déficits invisibles, y su potencial impacto en el proceso de rehabilitación, no existe una conceptualización clara de estos, ni de su impacto o abordaje terapéutico. La presente revisión utilizó la metodología PRISMA para sistematizar el conocimiento existente respecto a la definición de una LCA invisible, sus consecuencias, así como la utilidad de intervenciones psicoeducativas. Los resultados de la revisión sugieren que una LCA se define por carecer de marcadores visibles, ser difícil de pesquisar por terceros, siendo usualmente reconocida por quienes la padecen. Al no ser reconocida por otros, la LCA invisible contribuye a la discrepancia entre el self pre y post lesional, así como a la generación de expectativas no realistas. La invisibilidad de los déficits puede comprometer la adecuada derivación a servicios especializados de rehabilitación, así como la adherencia al tratamiento. Asimismo, puede dificultar la reinserción educacional debido a la errónea interpretación de cambios cognitivos y conductuales. En contextos laborales, puede comprometer la acomodación de la carga laboral, espacio de trabajo (ej. infraestructura, horarios), o el establecimiento de relaciones de apoyo con pares y jefatura. Si bien la psicoeducación es una intervención idónea para abordar los déficits invisibles, existen escasos programas que incorporen este problema como un elemento central.

Palabras Claves: Lesión Cerebral Adquirida, Déficit Invisibles, Discapacidad Invisible, Daño Cerebral Invisible, Psicoeducación.

An acquired Brain Injury (ABI) can cause a wide range of motor/sensorial, cognitive, behavioral and socioemotional deficits, impacting the process of community reintegration and decreasing mental health and quality of life. Clinicians and ABI survivors have stated that invisible deficits can generate important barriers for community reintegration. Despite this growing interest for invisible impairments and their impact in the rehabilitation process, to date there isn't a clear conceptualization of them, their impact and how to address them therapeutically. This review was conducted following PRISMA methodology for the systematic synthesis of knowledge related to invisible brain injuries, their definition, associated consequences and existing interventions. Data from this review suggests that an invisible brain injury is characterized by a lack of visual markers, a difficulty to be noticed by others and the exclusive recognition by patients themselves. Because they tend not to be recognized by others, invisible brain injuries contribute to enlarge the discrepancy between pre and post injury self, as well as the generation of unrealistic expectations towards the survivor. The invisibility of deficits can compromise the referral of survivors to specialized rehabilitation services or professionals, as well as adherence to treatment. Invisibility of impairments can also compromise the return to educational contexts due to misinterpretation of cognitive and behavioral changes. In working environments, invisible deficits can negatively impact the necessary accommodation of tasks, workload or routines, as well as the establishment of supporting relationships with peers and supervisors. Even when psychoeducation is an ideal intervention to promote awareness of invisible impairments, very few programs include this problem as a central element.

Keywords: Acquired Brain Injury, Invisible Disability, Invisible Deficit, Invisible Brain Injury, Psychoeducation

¹ Centro de Estudios en Neurociencia Humana y Neuropsicología Clínica (CENHN), Facultad de Psicología, Universidad Diego Portales. Santiago, Chile.

² Unidad de Neuropsicología Clínica (UNC), Facultad de Psicología, Universidad Diego Portales. Santiago, Chile.

INTRODUCCIÓN

El término Lesión Cerebral Adquirida (LCA), engloba un amplio espectro de lesiones cerebrales, las cuales pueden ser de tipo traumáticas (e.g. contusiones cerebrales producto de accidentes automovilísticos) o no traumáticas (e.g. Accidentes Cerebro Vasculares (ACV), infecciones o tumores cerebrales (Greenwald et al., 2003; Teasell et al., 2007)). Las LCAs son una de las principales causas de muerte y discapacidad a nivel mundial (World Health Organization, 2006), presentando una amplia gama de déficits motores/sensoriales, cognitivos, conductuales y socioemocionales (Chan et al., 2013; Greenwald et al., 2003; Winstein et al., 2016), pudiendo generar altos niveles de discapacidad (Sturm et al., 2002) y reducción en la calidad de vida (Díaz-Tapia et al., 2008). La manifestación de estos déficits puede variar en cada persona, dependiendo de factores neurológicos y de personalidad (Ben-Yishay & Diller, 2011). Recientemente, autores y sobrevivientes de LCA han sugerido que los cambios tras un daño cerebral deberían ser conceptualizados como “*visibles*” (e.g. lesiones físicas o dificultades motoras) o “*invisibles*” (e.g. alteraciones no evidentes) (Chamberlain, 2006; Gelech & Desjardins, 2011; McClure et al., 2008). Si bien el uso de este concepto es reciente en LCA, dicha distinción ya ha sido utilizada en otras patologías neurológicas y poblaciones con problemas de salud mental (Chamberlain, 2006; Rattray et al., 2019; Venville et al., 2016).

A la fecha, el conocimiento sobre los déficits invisibles en LCA ha provenido de los testimonios de sobrevivientes, quienes han enfatizado su relevancia para el ajuste emocional y reinserción a la comunidad. De acuerdo a Aurora Lassaletta (2019), psicóloga clínica y sobreviviente de un Traumatismo Craneano (Lassaletta, 2019b), los déficits invisibles más comunes pueden agruparse en cinco tipos: *cognitivos* (ej. fatiga, problemas atencionales y de memoria, dificultades ejecutivas) *conductuales* (ej. impulsividad, tendencia a la pasividad), *físicos* (alteración sensibilidad corporal), *emocionales* (ej. problemas de reactividad y regulación emocional) y vinculados a la *identidad* (ej. discontinuidad entre el yo pre y post lesión). Para una descripción detallada de la experiencia de cada uno de estos déficits por sobrevivientes ver Anexo 1. Si bien algunos autores han planteado anecdóticamente o en viñetas clínicas la relevancia de los déficits invisibles (Lowe et al., 2021), este problema continúa siendo desconocido y subestimado por la comunidad de profesionales e investigadores interesados en la rehabilitación neuropsicológica. Como consecuencia

la neurorehabilitación ha tendido a enfocarse en las consecuencias físicas y visibles (Lassaletta, 2019b; McClure et al., 2008) careciendo de una conceptualización clara respecto a los déficits invisibles que pueda orientar su investigación y evaluación/intervención en contextos clínicos

Los procesos de neuro-rehabilitación, y en especial la rehabilitación neuropsicológica, han utilizado sistemáticamente la psicoeducación como una herramienta terapéutica para abordar déficits cognitivos, socioemocionales y conductuales (Wilson et al., 2009). La psicoeducación ha sido definida como el proceso educativo de entrega de información respecto de la LCA, sus consecuencias, manejo y pronóstico (Ekhtiari et al., 2017). Esta información puede ser entregada a sobrevivientes, familiares, amigos o personal de salud. Lamentablemente los programas existentes de psicoeducación en LCA no han considerado como un contenido central la naturaleza invisible de algunas alteraciones cognitivas o conductuales, contribuyendo a su omisión. Si tomamos como ejemplo el manual de rehabilitación neuropsicológica de Wilson, Gracey, Evans y Bateman (2008), donde se describen diversos talleres de psicoeducación, el problema de la invisibilidad de las alteraciones cognitivas y conductuales no es considerada en absoluto. En otras palabras, la psicoeducación clásica utilizada por los programas de rehabilitación neuropsicológica parece no reconocer que estos déficits, y su manifestación, son difíciles de comprender por otros y pueden generar reacciones escépticas y poco empáticas.

En vista del creciente interés por comprender la naturaleza de los déficits invisibles después de una LCA, sus potenciales consecuencias y posibles abordajes terapéuticos, el presente artículo tiene como objetivo revisar la literatura existente en relación a tres preguntas: a) cómo se han definido los déficits invisibles; b) cuáles son las implicancias de los déficits invisibles descritas en la literatura; c) qué tipo de intervenciones psicoeducativas se han diseñado específicamente para abordar los déficits invisibles. De esta manera, se busca abordar cómo ha sido utilizado el concepto de “*déficit invisibles*” en la literatura académica, así como también abordar su impacto en programas de rehabilitación.

METODOLOGÍA

Protocolo. Se realizó un scoping review de la literatura académica siguiendo los lineamientos entregados por JBI (*Joanna Briggs Institute*) (Peters et al., 2015) y haciendo uso de la extensión de los lineamientos PRISMA (*Preferred*

Reporting Items for Systematic Reviews and Meta-Analyses) para el reporte de scoping reviews (Tricco et al., 2018).

Criterios de elegibilidad. En función de los objetivos propuestos en esta revisión, se incluyeron dos tipos de artículos/estudios. En primer lugar, se incluyeron estudios sobre cualquier tipo de lesión cerebral adquirida (e.g. tumores, encefalitis, accidentes cerebro vasculares) que abordaran de manera teórica o empírica el daño cerebral invisible. Por otro lado, se incluyeron artículos sobre intervenciones psicoeducativas diseñadas para abordar el daño invisible. Se evaluó todo tipo de artículo, independiente del diseño de investigación. Todos los artículos revisados se encontraban disponibles en inglés y/o español. No se aplicaron restricciones temporales en la realización de la búsqueda.

Se excluyeron todos aquellos artículos cuyo énfasis estaba puesto en la prevalencia y prevención, así como también aquellos que no trataban sobre lesiones cerebrales invisibles. Asimismo, se excluyeron todos aquellos artículos cuyas intervenciones no eran de carácter psicoeducativas.

Fuentes de información. Se realizó una búsqueda comprensiva de la literatura en dos bases de datos electrónicas (Web of Science y EBSCO). La revisión de la literatura se realizó entre septiembre y octubre del año 2020. Además, se revisaron plataformas de organizaciones orientadas a la educación y entrega de recomendaciones sobre LCA (e.g. Headway, SYNAPSE).

Proceso de búsqueda. Se desarrolló una estrategia de búsqueda siguiendo los lineamientos PRESS (Peer Review of Electronic Search Strategies) (McGowan et al., 2016), la cual fue adaptada y aplicada para las dos bases de datos revisadas (Anexo 2). Las palabras clave de búsqueda estuvieron relacionadas al término daño invisible (e.g. *Invisible Brain Injury*, *Invisible Cognitive Disability*), al concepto lesión cerebral adquirida (e.g. *Acquired Brain Injury*, *Brain Injury*) y psicoeducación (*Psychoeducation*). Se utilizaron todos los campos de búsqueda, es decir, se buscó la aparición de estos términos en cualquier lugar del texto.

Selección de fuentes de evidencia. Los resultados de las búsquedas en bases de datos y páginas web fueron exportados a Microsoft Excel (Microsoft Corporation, 2018). Se eliminaron los artículos duplicados. Los artículos fueron revisados para evaluar su inclusión por título, excluyendo aquellos que no cumplían con los criterios de inclusión. Los artículos restantes fueron revisados por abstract utilizando Microsoft Excel (Microsoft Corporation, 2018), con detalles sobre los artículos que posibilitaron la toma de decisión sobre la inclusión/

exclusión. Este proceso fue realizado por la primera autora (A.G.C.), siendo las dificultades encontradas en el proceso resueltas utilizando consenso con el segundo autor (C.S).

Extracción de información. Se desarrolló una tabla en Microsoft Excel con instrucciones detalladas para la extracción de información. Esta tabla estaba guiada por los objetivos de la presente revisión, codificándose información como: i) caracterización de los artículos, ii) definición de daño invisible, iii) consecuencias asociadas al daño invisible y iv) características de programas/intervenciones psicoeducativas para abordar el daño invisible.

Ítems de información. En primer lugar los artículos fueron revisados y codificados respecto a su caracterización: i) Año de publicación; ii) Población objetivo; iii) Diseño del estudio/Tipo de artículo y iv) Tamaño muestral. Los artículos también fueron revisados en función de la definición de déficit invisible y las implicancias de estos. Finalmente, se caracterizaron intervenciones psicoeducativas orientadas a los déficits invisibles en función del ambiente psicosocial, público objetivo, el objetivo del estudio y la frecuencia de la intervención (en los casos que aplicara).

Proceso de síntesis. Los datos fueron resumidos, en función de las categorías antes mencionadas, haciendo uso de una metodología narrativa y siguiendo los lineamientos para scoping reviews (Arksey & O'Malley, 2005).

RESULTADOS

Selección de fuentes de evidencia. La búsqueda inicial arrojó un total de 59 artículos académicos y 12 más fueron encontrados mediante búsqueda manual de referencias. Tras el proceso de eliminación de duplicados, quedaron 34 artículos a evaluar para inclusión. Luego de la evaluación en función del título 28 artículos fueron seleccionados. La codificación de abstract en base a los criterios de elegibilidad excluyó 18 artículos. Todos los artículos seleccionados disponibles fueron codificados en función del texto completo (Figura 1).

Características de las fuentes de evidencia. Del total de artículos incluidos, 7 de ellos entregaban alguna definición sobre daño invisible y sus consecuencias (Chamberlain, 2006; Childers & Hux, 2016; Irwin & Fortune, 2014; Lorenz, 2010; Rattray et al., 2019; Syma, 2018; Venville et al., 2016), mientras que 10 de los artículos referían a intervenciones psicoeducativas sobre el daño invisible (Backhaus et al., 2010; Baseotto & Godfree, 2017; Donnelly et al., 2020; Gallagher et al., 2019; Irwin &

Fortune, 2014; McDonald et al., 2021; Renaud et al., 2020; Snell et al., 2020; Twamley et al., 2014; von Mensenkampff et al., 2015). Respecto a la metodología de los estudios, 7 de ellos son de tipo cualitativo (Baseotto & Godfree, 2017; Chamberlain, 2006; Childers & Hux, 2016; Donnelly et al., 2020; Irwin & Fortune, 2014; Lorenz, 2010; McDonald et al., 2021), cuatro de tipo cuantitativo (Backhaus et al., 2010; Renaud et al., 2020; Twamley et al., 2014; von Mensenkampff et al., 2015); dos de metodología mixta (Ratray et al., 2019; Snell et al., 2020) y dos artículos de carácter teórico (Syma, 2018; Venville et al., 2016)

Respecto a la población sobre la cual refieren estos artículos, ocho de ellos están destinados a lesiones cerebrales traumáticas (Chamberlain, 2006; Childers & Hux, 2016; Donnelly et al., 2020; McDonald et al., 2021; Ratray et al., 2019; Renaud et al., 2020; Snell et al., 2020; Twamley et al., 2014), seis sobre lesión cerebral general (Backhaus et al., 2010; Baseotto & Godfree, 2017; Irwin & Fortune, 2014; Lorenz, 2010; Syma, 2018; Venville et al., 2016) y uno sobre accidentes cerebro vasculares (Gallagher et al., 2019). La Tabla 1 presenta la caracterización de todos los estudios incluidos en la presente revisión, especificando el motivo de inclusión, el tipo de estudio y la población a la cual estaba dirigido.

SÍNTESIS DE RESULTADOS

Definición de Déficit Invisible.

A partir de la revisión de los artículos es posible dar cuenta que los autores coinciden al definir y caracterizar los déficits invisibles como no aparentes a simple vista dado que *carecen de marcadores visibles* para su identificación (ej. uso de muletas, silla de ruedas), lo que los vuelve *difíciles de pesquisar* incluso por profesionales de la salud o rehabilitación, siendo usualmente *reconocidos por quienes los padecen* (Childers & Hux, 2016; Gallagher et al., 2019; Irwin & Fortune, 2014; Lorenz, 2010; Ratray et al., 2019; Syma, 2018; Venville et al., 2016). Debido a la ausencia de marcadores visibles los sobrevivientes suelen ser percibidos por otros como *idénticos a su self pre-lesional*, generando una discrepancia con la percepción propia, así como una experiencia de no comprensión. Las dificultades invisibles más frecuentemente mencionadas por los pacientes son la fatiga, el dolor, los mareos, las dificultades emocionales y algunas disfunciones cognitivas (Chamberlain, 2006; Ratray et al., 2019; Syma, 2018; Venville et al., 2016).

Implicancias de los Déficit Invisibles

Del total de artículos revisados, cuatro de ellos refieren al impacto negativo de los déficits invisibles en la vida de las personas debido a que estas dificultades son infravaloradas por profesionales, familiares y amigos, generando la expectativa de que el sobreviviente se comporte o rinda como siempre lo ha hecho (Chamberlain, 2006; Childers & Hux, 2016; Ratray et al., 2019; Schutz et al., 2010).

Tres de los artículos revisados refieren específicamente a las implicancias negativas de los déficits invisibles en el contexto educacional (Gallagher et al., 2019; Stone, 2005; Venville et al., 2016), señalando que estos pueden convertirse en barreras para la participación en educación postsecundaria (Venville et al., 2016) debido al desconocimiento y escasa comprensión de docentes y compañeros, así como situaciones de discriminación (Gallagher et al., 2019; Stone, 2005). Otra de las barreras que pueden general los déficits invisibles en el contexto educacional, es la interpretación de cambios neuroconductuales como rasgos conflictivos de personalidad y no como consecuencia directa de la lesión (e.g. irresponsabilidad, falta de compromiso) (Gallagher et al., 2019; Stone, 2005). Asimismo, se ha señalado que la población joven sufre mayor dificultad dado que las LCAs son comúnmente asociadas a poblaciones adultas (Gallagher et al., 2019; Stone, 2005). En los artículos revisados se propone que estas dificultades en contextos educacionales y poblaciones jóvenes implican también una disminución de la búsqueda de procesos de rehabilitación e impactan en la continuidad de los mismos (Gallagher et al., 2019; Stone, 2005; Venville et al., 2016).

Tres artículos abordan las consecuencias de los déficits invisibles en contextos laborales (Colella, 2001; Paetzold et al., 2008; Syma, 2018), particularmente en el proceso de reinserción laboral (Colella, 2001; Paetzold et al., 2008; Syma, 2018). Se señala que la invisibilidad de los déficits puede comprometer el adecuado análisis y necesaria acomodación de la carga laboral, espacio de trabajo (ej. infraestructura, horarios), o el establecimiento de relaciones de apoyo y no conflictivas con pares y jefatura. Se describe, por ejemplo, que la invisibilidad de los déficits puede generar sentimientos de "injusticia" en los demás trabajadores, poniendo en duda la veracidad de las dificultades y disminuyendo la disponibilidad de apoyo (Colella, 2001; Paetzold et al., 2008).

Psicoeducación y Déficit Invisibles

Del total de artículos y recursos sobre psicoeducación que consideran los déficits invisibles, cuatro de ellos

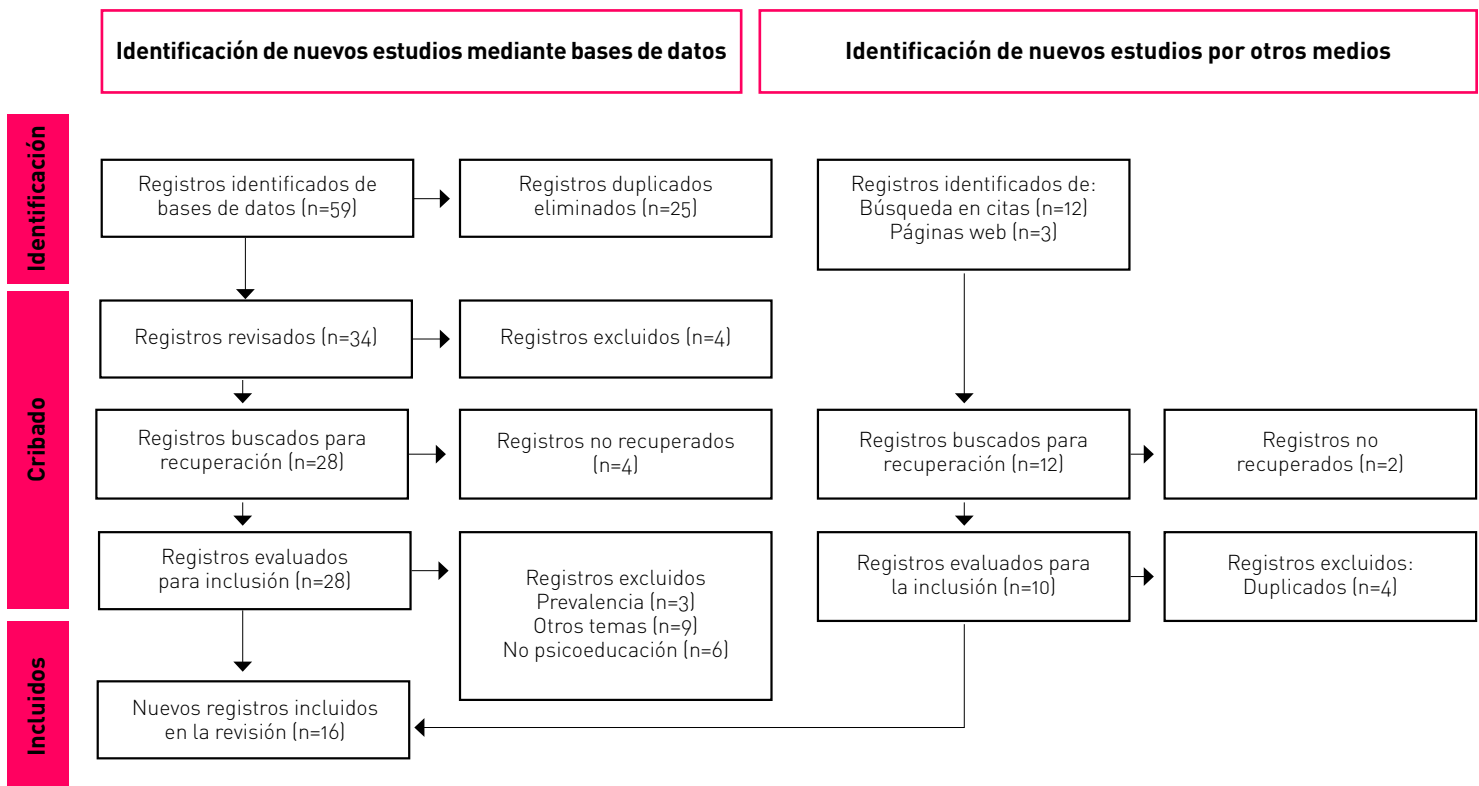


Figura 1. Diagrama de revisión de artículos. El diagrama presenta una sistematización de los artículos revisados en las distintas etapas del proceso de selección y codificación para llegar a la muestra final.

estaban enfocados a la psicoeducación del entorno cercano (Backhaus et al., 2010; Baseotto & Godfree, 2017; McDonald et al., 2021; Renaud et al., 2020), tres orientados al entorno educacional (Venville et al., 2016) y siete a contextos laborales (Colella, 2001; Greenwald et al., 2003; Paetzold et al., 2008; Targett & Wehman, 2011; West, 1995). El público objetivo al que se orientaban las recomendaciones y proceso psicoeducativo varió entre pacientes (Baseotto & Godfree, 2017; Renaud et al., 2020), pacientes/ cuidadores (Backhaus et al., 2010; McDonald et al., 2021), supervisores y colegas (Colella, 2001; Paetzold et al., 2008; Targett & Wehman, 2011) y compañeros de clases (Venville et al., 2016). Las temáticas abordadas por los artículos fueron variadas, siendo las más comunes el entendimiento de la lesión y sus consecuencias invisibles (Colella, 2001; McDonald et al., 2021; Paetzold et al., 2008; Venville et al., 2016) así como la inclusión social (Targett & Wehman, 2011; West, 1995).

De los artículos revisados referentes a la psicoeducación sobre déficits invisibles, cuatro de ellos enfatizaron la importancia de esta intervención debido a su impacto positivo en el cuidado de la salud, la funcionalidad en la vida diaria y la calidad de vida. También se asoció la psicoeducación a la reducción de la sintomatología ansiosa y depresiva, teniendo un impacto positivo no sólo en el paciente sino también en la familia (Baseotto & Godfree, 2017; Couchman et al., 2014; Lukens & McFarlane, 2004; Smith & Testani-Dufour, 2002). Dos de los artículos incluidos proponen que existen dos tipos de psicoeducación: formal (i.e. a partir de la entrega de información por parte de profesionales), e informal (a partir de la experiencia propia o de otros) (Baseotto & Godfree, 2017; Couchman et al., 2014).

En relación a los objetivos de la psicoeducación, cinco artículos abordan explícitamente el problema de los déficits invisibles (Donnelly et al., 2020; Ekhtiari et al., 2017; McDonald et al., 2021; Snell et al., 2020; Twamley et al., 2014), describiendo como principales metas: a) entendimiento de la lesión; b) entendimiento de las consecuencias orgánicas (cerebrales) y comportamentales (Donnelly et al., 2020; Ekhtiari et al., 2017; Snell et al., 2020); c) identificación

Tabla 1. Caracterización de los estudios incluidos en la revisión y motivo de inclusión.

Referencia	Título	Motivo de Inclusión	Tipo de Estudio	Población	Tamaño Muestral
Chamberlain, 2006	The experience of surviving traumatic brain injury	Definición invisible	Cualitativo	Lesión Cerebral Traumática	60 participantes
Backhaus et al., 2010	Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers	Intervención psicoeducativa	Cuantitativo (RCT)	Lesión Cerebral	40 participantes
Lorenz, 2010	Visual metaphors of living with brain injury: exploring and communicating lived experience with an invisible injury	Definición invisible	Cualitativo	Lesión Cerebral	7 participantes
Twamley et al., 2014	Cognitive Symptom Management and Rehabilitation Therapy (CogSMART) for Veterans with traumatic brain injury: Pilot randomized controlled trial	Intervención psicoeducativa	Cuantitativo (Piloto RCT)	Lesión Cerebral Traumática	50 participantes
Irwin, 2014	Schools-based interventions for reducing stigmatization of acquired brain injury: the role of interpersonal contact and visible impairment	Definición invisible e Intervención psicoeducativa	Cualitativo	Lesión Cerebral Adquirida	408 participantes
von Mensenkampff et al., 2015	The value of normalization: Group therapy for individuals with brain injury.	Intervención psicoeducativa	Cuantitativo (Grupo control)	Lesión Cerebral	45 participantes
Childers & Hux, 2016	Invisible Injuries: The Experiences of College Students with Histories of Mild Traumatic Brain Injury	Definición invisible	Cualitativo	Lesión Cerebral Traumática	5 participantes
Venville et al., 2016	Supporting Students with Invisible Disabilities: A Scoping Review of Postsecondary Education for Students with Mental Illness or an Acquired Brain Injury	Definición invisible	Teórico	Lesión Cerebral Adquirida	N/A
Baseotto & Godfree, 2017	Evaluating a brief group psychoeducation intervention on managing the consequences of brain injury for clients with a brain injury and their family/carers	Intervención psicoeducativa	Cualitativo	Lesión Cerebral	152 participantes
Syma, 2019	Invisible disabilities: perceptions and barriers to reasonable accommodations in the workplace	Definición invisible	Teórico	Lesión Cerebral	N/A
McDonald et al., 2019	Providing on-line support to families of people with brain injury and challenging behaviour: A feasibility study	Intervención psicoeducativa	Cualitativo	Lesión Cerebral Traumática	6 participantes
Rattray et al., 2019	The Long and Winding Road to Postsecondary Education for US Veterans With Invisible Injuries	Definición invisible	Mixto (Entrevistas y Cuestionario)	Lesión Cerebral Traumática	38 participantes
Gallagher, McClure, & McDowall, 2019	Why do people misunderstand stroke symptoms? How background knowledge affects causal attributions for ambiguous stroke symptoms	Intervención psicoeducativa	Cuantitativo (Casos cruzados)	Accidente Cerebro Vascular	143 participantes
Donnelly, Goldberg, & Fournier, 2020	A qualitative study of LoveYourBrain Yoga: a group-based yoga with psychoeducation intervention to facilitate community integration for people with traumatic brain injury and their caregivers.	Intervención psicoeducativa	Cualitativo	Lesión Cerebral Traumática	13 participantes
Renaud et al., 2020	Process evaluation of 'Brains Ahead!': an intervention for children and adolescents with mild traumatic brain injury within a randomized controlled trial	Intervención psicoeducativa	Cuantitativo (Estudio Prospectivo)	Lesión Cerebral Traumática	60 participantes
Snell et al., 2020	Wrestling with uncertainty after mild traumatic brain injury: a mixed methods study	Intervención psicoeducativa	Mixto (Caso-Control y Entrevistas)	Lesión Cerebral Traumática	76 participantes

RCT: Randomized Controlled Trials.

N/A: No aplica.

realista de fortalezas y debilidades de cada persona (McDonald et al., 2021). Algunos autores enfatizaron la importancia de realizar una entrega temprana de información sobre déficits invisibles, incluso señalando que la psicoeducación debería ocurrir antes de iniciarse la rehabilitación, de modo de facilitar la comprensión de la lesión y sus consecuencias, promover el acceso temprano a rehabilitación, así como la adherencia al tratamiento (Gallagher et al., 2019; von Mensenkampff et al., 2015) (Tabla 2).

Tabla 2. Caracterización de intervenciones y recursos psicoeducativos para abordar déficits invisibles.

Referencia	Público Objetivo	Tipo de Intervención	Temáticas	Duración y Frecuencia
Renaud et al., 2020	Pacientes	Intervención Grupal	Participación, reconocimiento y anticipación de síntomas	2 sesiones (2 a 8 semanas post lesión)
Backhaus et al., 2010	Pacientes y Cuidadores	Intervención Grupal	Manejo del estrés	12 sesiones (2 horas cada una)
Baseotto & Godfree, 2017	Pacientes	Intervención Grupal	Experiencias personales	4 sesiones semanales (2 horas cada una)
McDonald et al., 2019	Pacientes y Cuidadores	Intervención Grupal	Entendimiento de la lesión y sus consecuencias, autocuidado cuidadores	N/R
Headway	Pacientes, Compañeros y Profesores	Guía/Recursos Online	Entendimiento de la lesión, retorno académico	N/A
SYNAPSE	Pacientes, Compañeros y Profesores	Guía/Recursos Online	Entendimiento de la lesión, retorno académico	N/A
Venville et al., 2016	Pacientes, Compañeros y Profesores	Intervención Grupal e Individual	Consecuencias de la lesión y su impacto, retorno académico	N/A
Colella, 2001	Supervisores y Colegas	Intervención Grupal e Individual	Entrega de información, psicoeducación y trabajo en el ambiente laboral	N/A
Paetzold et al., 2008	Supervisores y Colegas	Intervención Grupal e Individual	Entrega de información, psicoeducación y trabajo en el ambiente laboral	N/A
West, 1995	Pacientes y Colegas	Intervención Grupal	Reconocimiento de posibles dificultades, inclusión social	N/A
SYNAPSE	Pacientes, Supervisores y Colegas	Guía/Recursos Online	Ajuste laboral y reintegro	N/A
BIAUSA	Pacientes, Supervisores y Colegas	Guía/Recursos Online	Ajuste laboral y reintegro	N/A
Headway	Pacientes, Supervisores y Colegas	Guía/Recursos Online	Ajuste laboral y reintegro	N/A
Targett & Wehman, 2011	Pacientes y Colegas	Individual	Reconocimiento de posibles dificultades, inclusión social	N/A

N/R: No reporta.

N/A: No aplica.

relevancia de los déficits invisibles es que pueden constituirse en obstáculos para la identificación y comprensión de dificultades y necesidades, pudiendo comprometer la disponibilidad de apoyo necesario y actitudes empáticas de

DISCUSIÓN

El propósito de esta investigación fue sistematizar la evidencia existente respecto a los déficits invisibles que se generan tras una LCA, así como también identificar y describir intervenciones psicoeducativas diseñadas para abordar específicamente este tipo de déficits.

Respecto a la primera pregunta, la literatura sugiere que los déficits invisibles se caracterizan por la ausencia de marcadores físicos o visuales que faciliten su identificación. Los déficits invisibles pueden ser de diversa naturaleza; cognitivos, conductuales, emocionales, físicos o vinculados al cambio en la identidad. De acuerdo, a diversos autores, la

familiares, colegas o profesionales de la salud. Los artículos revisados sugieren que existen ventajas y desventajas asociadas a los déficits invisibles. La principal ventaja parece ser la disminución de la experiencia de discriminación debido a una 'aparente' normalidad. No obstante, el costo de dicha aparente normalidad puede ser la experiencia de aislamiento

y no comprensión respecto a las dificultades experimentadas, frecuentes malos entendidos y atribuciones negativas al sobreviviente, así como la no derivación oportuna a servicios de rehabilitación especializados. Al respecto, desde la psicología social se han ofrecido importantes insights, en relación a cómo los sobrevivientes experimentan interacciones estigmatizadoras debiendo aceptar, ocultar o rechazar el estigma social (Hagger & Riley, 2019; Riley & Hagger, 2015). Ha sido propuesto incluso que los déficits invisibles son particularmente fuente de estigma social debido a la ausencia de marcadores visibles y falta de información sobre la LCA en la población general (Bracho-Ponce et al., 2022). No es de extrañar entonces que un tema común en muchos sobrevivientes con dificultades invisibles sea el anhelo de contar con marcadores visuales (ej. dificultad en marcha, lesiones óseas, cicatrices, bastones) para sentirse reconocidos y evitar interacciones negativas (Lowe et al., 2021). Otro aspecto a considerar en relación a los déficits invisibles es su potencial impacto negativo en el proceso de reconstrucción de identidad. Este proceso demanda la re-articulación del self pre y post-lesión, no sólo a nivel personal sino también social. Aquí las etiquetas negativas atribuidas por otros al sobreviviente (Nochi, 1998a), o la incongruencia entre autopercepción y percepción de terceros puede comprometer el proceso de generar una positiva nueva versión del self post lesión (Nochi, 1998b). Futuros estudios deberán levantar datos para explorar la potencial relación entre déficits invisibles, estigma y reconstrucción de identidad. Asimismo, será importante explorar qué déficits invisibles son más relevantes o problemáticos, instalando mayores barreras a la reinserción comunitaria o rehabilitación.

Nuestra revisión sugiere que la psicoeducación formal e informal es una herramienta idónea para abordar los déficits invisibles y su expresión en diversos contextos (familiares, educacionales o laborales). Sabemos que las intervenciones psicoeducativas con paradigmas grupales son especialmente efectivas en promover la autoeficacia y bienestar emocional, por medio de la exposición temática y el compartir con otros sobrevivientes la propia experiencia (Backhaus et al., 2010; Baseotto & Godfree, 2017; Couchman et al., 2014; Donnelly et al., 2020). La psicoeducación en contexto grupal puede ser particularmente efectiva en ayudar a visibilizar, y por lo tanto normalizar déficits invisibles, generando una experiencia de conexión, solidaridad y “nueva normalidad” (Salas et al., 2018). Una de las limitaciones de la literatura es que la información existente respecto a

psicoeducación tendió a ser escasa y más bien genérica, es decir, estaba usualmente dirigida a un amplio número de problemas donde en el mejor de los casos se mencionan los déficits invisibles. Creemos que esto puede deberse a un desconocimiento de la centralidad de este problema en profesionales de la rehabilitación que diseñan dichas intervenciones. Por ejemplo, el término “invisible” no aparece utilizado en el manual *Neuropsychological Rehabilitation: Theory, Models, Therapy and Outcome* (Wilson et al., 2009), el libro que a la fecha realiza la descripción más detallada de intervenciones grupales de psicoeducación para diversos problemas luego de una LCA. En contraste, el término invisible ha ocupado un lugar central como problemática en numerosas publicaciones realizadas por sobrevivientes (e.g. [Dewar, 2017; Lassaletta, 2019a; 2017; Starr, 2019; Zellmer, 2015]). Futuros estudios deberán explorar qué déficits invisibles son más relevantes para la educación de diversas poblaciones etarias, o necesarios de abordar en diversos contextos de rehabilitación (familiar, educacional, laboral). Entender el nivel de conocimiento del público en general respecto a la lesión cerebral será asimismo relevante, esto en base a estudios que han mostrado que un mayor desconocimiento se relaciona con mayor estigma y menor predisposición a interactuar (Bracho-Ponce et al., 2022; Frias et al., 2020; Ostwald et al., 1999). En esta línea, será también importante replicar y conocer el impacto en el público general que puedan tener campañas de concientización respecto a los déficits invisibles, como la campaña de Headway “*See the hidden me*” (ve mi yo oculto)¹.

Conflicto de interés

Los autores declaran que el presente estudio se realizó en ausencia de cualquier relación financiera o comercial que pudiese significar un potencial conflicto de interés.

Contribuciones de los autores

Ambos autores trabajaron en la conceptualización, realización de la revisión y redacción del presente manuscrito.

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1 <https://www.headway.org.uk/news-and-campaigns/campaigns/see-the-hidden-me/>

REFERENCIAS

- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32.
- Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., & Malec, J. F. (2010). Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. *Archives of Physical Medicine and Rehabilitation*, 91(6), 840–848.
- Baseotto, M., & Godfree, R. (2017). Evaluating a brief group psychoeducation intervention on managing the consequences of brain injury for clients with a brain injury and their family/carers. *Clinical Psychology Forum*, 292, 41–46.
- Ben-Yishay, Y., & Diller, L. (2011). *Handbook of Holistic Neuropsychological Rehabilitation: Outpatient Rehabilitation of Traumatic Brain Injury*. Oxford University Press, USA.
- Bracho-Ponce, M. J., Grasso-Cladera, A., & Salas, C. (2022). "I am not who you think I am": public stigma and invisible brain injury ('No soy quien creen que soy': estigma público y daño cerebral invisible). *Studies in*. <https://www.tandfonline.com/doi/abs/10.1080/02109395.2021.2006947>
- Chamberlain, D. J. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*, 54(4), 407–417.
- Chan, V., Zagorski, B., Parsons, D., & Colantonio, A. (2013). Older adults with acquired brain injury: a population based study. *BMC Geriatrics*, 13, 97.
- Childers, C., & Hux, K. (2016). Invisible injuries: The experiences of college students with histories of mild traumatic brain injury. *Journal of Postsecondary Education and Disability*, 29(4), 389–405.
- Colella, A. (2001). Coworker Distributive Fairness Judgments of the Workplace Accommodation of Employees with Disabilities. *AMRO*, 26(1), 100–116.
- Couchman, G., McMahon, G., Kelly, A., & Ponsford, J. (2014). A new kind of normal: qualitative accounts of Multifamily Group Therapy for acquired brain injury. *Neuropsychological Rehabilitation*, 24(6), 809–832.
- Dewar, B.-K. (2017). Life after encephalitis: a narrative approach. *Neuropsychological Rehabilitation*, 1–2.
- Díaz-Tapia, V., Gana, J., Sobarzo, M., Jaramillo-Muñoz, A., & Illanes-Díez, S. (2008). Estudio sobre la calidad de vida en pacientes con accidente vascular cerebral isquémico. *Revista de Neurología*, 46(11), 652–655.
- Donnelly, K. Z., Goldberg, S., & Fournier, D. (2020). A qualitative study of LoveYourBrain Yoga: a group-based yoga with psychoeducation intervention to facilitate community integration for people with traumatic brain injury and their caregivers. *Disability and Rehabilitation*, 42(17), 2482–2491.
- Ekhtiari, H., Rezapour, T., Aupperle, R. L., & Paulus, M. P. (2017). Chapter 10 - Neuroscience-informed psychoeducation for addiction medicine: A neurocognitive perspective. In T. Calvey & W. M. U. Daniels (Eds.), *Progress in Brain Research* (Vol. 235, pp. 239–264). Elsevier.
- Frias, C. E., Garcia-Pascual, M., Montoro, M., Ribas, N., Risco, E., & Zabalegui, A. (2020). Effectiveness of a psychoeducational intervention for caregivers of People With Dementia with regard to burden, anxiety and depression: A systematic review. *Journal of Advanced Nursing*, 76(3), 787–802.
- Gallagher, J., McClure, J., & McDowall, J. (2019). Why do people misunderstand stroke symptoms? How background knowledge affects causal attributions for ambiguous stroke symptoms. *Brain Injury: [BI]*, 33(8), 1070–1077.
- Gelech, J. M., & Desjardins, M. (2011). I am many: the reconstruction of self following acquired brain injury. *Qualitative Health Research*, 21(1), 62–74.
- Greenwald, B. D., Burnett, D. M., & Miller, M. A. (2003). Congenital and acquired brain injury. 1. Brain injury: epidemiology and pathophysiology. *Archives of Physical Medicine and Rehabilitation*, 84(3 Suppl 1), S3–S7.

- Hagger, B. F., & Riley, G. A. (2019). The social consequences of stigma-related self-concealment after acquired brain injury. *Neuropsychological Rehabilitation, 29*(7), 1129–1148.
- Irwin, L. G., & Fortune, D. G. (2014). Schools-based interventions for reducing stigmatization of acquired brain injury: the role of interpersonal contact and visible impairment. *Archives of Clinical Neuropsychology: The Official Journal of the National Academy of Neuropsychologists, 29*(2), 194–205.
- Lassaletta, A. (2019a). The invisible brain injury. In *The Invisible Brain Injury* (pp. 3–11). Routledge.
- Lassaletta, A. (2019b). *The Invisible Brain Injury: Cognitive Impairments in Traumatic Brain Injury, Stroke and other Acquired Brain Pathologies*. Routledge.
- Lassaletta Atienza, A., Bilbao, Á., Bize, A., & Pajares, S. (2017). *El daño cerebral invisible*. Madrid: EOS.
- Lorenz, L. S. (2010). Visual metaphors of living with brain injury: exploring and communicating lived experience with an invisible injury. *Visual Studies, 25*(3), 210–223.
- Lowe, N., Crawley, L., Wilson, C., & Waldron, B. (2021). “Lonely in my head”: The experiences of loneliness in individuals with brain injury. *British Journal of Health Psychology, 26*(2), 444–463.
- Lukens, E. P., & McFarlane, W. R. (2004). Psychoeducation as Evidence-Based Practice: Considerations for Practice, Research, and Policy. *Brief Treatment & Crisis Intervention, 4*(3). <http://triggered.stanford.clockss.org/ServeContent?url=http://btci.stanford.clockss.org/%2Fcgi%2F reprint%2F4%2F3%2F205.pdf>
- McClure, J., Buchanan, S., McDowall, J., & Wade, K. (2008). Attributions for behaviours of persons with brain injury: the role of perceived severity and time since injury. *Brain Injury: [BI], 22*(9), 639–648.
- McDonald, S., Trimmer, E., Newby, J., Grant, S., Gertler, P., & Simpson, G. K. (2021). Providing on-line support to families of people with brain injury and challenging behaviour: A feasibility study. *Neuropsychological Rehabilitation, 31*(3), 392–413.
- McGowan, J., Sampson, M., Salzwedel, D. M., Cogo, E., Foerster, V., & Lefebvre, C. (2016). PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *Journal of Clinical Epidemiology, 75*, 40–46.
- Microsoft Corporation. (2018). *Microsoft Excel* (2019 [16.0]) [Computer software]. <https://office.microsoft.com/excel>
- Nochi, M. (1998a). “Loss of self” in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine, 46*(7), 869–878.
- Nochi, M. (1998b). Struggling with the labeled self: people with traumatic brain injuries in social settings. *Qualitative Health Research, 8*(5), 665–681.
- Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist, 39*(3), 299–309.
- Paetzold, R. L., García, M. F., Colella, A., Ren, L. R., Triana, M. del C., & Ziebro, M. (2008). Perceptions of People with Disabilities: When is Accommodation Fair? *Basic and Applied Social Psychology, 30*(1), 27–35.
- Peters, M., Godfrey, C., McInerney, P., Soares, C. B., Khalil, H., & Parker, D. (2015). Methodology for JBI scoping reviews. In *The Joanna Briggs Institute Reviewers Manual 2015* (pp. 3–24). Joanna Briggs Institute.
- Ratray, N. A., True, G., Natividad, D. M., Salyers, M. P., Frankel, R. M., & Kukla, M. (2019). The long and winding road to postsecondary education for U.S. veterans with invisible injuries. *Psychiatric Rehabilitation Journal, 42*(3), 284–295.
- Renaud, M. I., Klees, C., van Haastregt, J. C., Catsman-Berrevoets, C. E., van de Port, I. G., Lambregts, S. A., & van Heugten, C. M. (2020). Process evaluation of “Brains Ahead!”: an intervention for children and adolescents with mild traumatic brain injury within a randomized controlled trial. *Clinical Rehabilitation, 34*(5), 688–697.
- Riley, G. A., & Hagger, B. F. (2015). Disclosure of a stigmatized identity: A qualitative study of the reasons why people

- choose to tell or not tell others about their traumatic brain injury. *Brain Injury: [BI]*, 29(12), 1480–1489.
- Salas, C. E., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. A. J. (2018). "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological Rehabilitation*, 28(7), 1161–1178.
- Schutz, L. E., Rivers, K. O., McNamara, E., Schutz, J. A., & Lobato, E. J. (2010). Traumatic brain injury in K-12 students: Where have all the children gone? *International Journal of Special Education*, 25(2), 55–71.
- Smith, M. S., & Testani-Dufour, L. (2002). Who's teaching whom? A study of family education in brain injury. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, 27(6), 209–214.
- Snell, D. L., Martin, R., Surgenor, L. J., Siegert, R. J., Hay-Smith, E. J. C., Melzer, T. R., Anderson, T. J., & Hooper, G. J. (2020). Wrestling with uncertainty after mild traumatic brain injury: a mixed methods study. *Disability and Rehabilitation*, 42(14), 1942–1953.
- Starr, C. J. (2019). *To Root & To Rise: Accepting Brain Injury* (S. Kay (ed.)). Spiral Path Publishing.
- Stone, S. D. (2005). Reactions to invisible disability: the experiences of young women survivors of hemorrhagic stroke. *Disability and Rehabilitation*, 27(6), 293–304.
- Sturm, J. W., Dewey, H. M., Donnan, G. A., Macdonell, R. A. L., McNeil, J. J., & Thrift, A. G. (2002). Handicap after stroke: how does it relate to disability, perception of recovery, and stroke subtype?: the north North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke; a Journal of Cerebral Circulation*, 33(3), 762–768.
- Syma, C. (2018). Invisible disabilities: perceptions and barriers to reasonable accommodations in the workplace. *Library Management*, 40(1/2), 113–120.
- Targett, P., & Wehman, P. (2011). Return to Work After Traumatic Brain Injury: A Supported Employment Approach. In I. Z. Schultz & E. S. Rogers (Eds.), *Work Accommodation and Retention in Mental Health* (pp. 277–294). Springer New York.
- Teasell, R., Bayona, N., Marshall, S., Cullen, N., Bayley, M., Chundamala, J., Villamere, J., Mackie, D., Rees, L., Hartridge, C., Lippert, C., Hilditch, M., Welch-West, P., Weiser, M., Ferri, C., McCabe, P., McCormick, A., Aubut, J.-A., Comper, P., ... Tu, L. (2007). A systematic review of the rehabilitation of moderate to severe acquired brain injuries. *Brain Injury: [BI]*, 21(2), 107–112.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, 169(7), 467–473.
- Twamley, E. W., Jak, A. J., Delis, D. C., Bondi, M. W., & Lohr, J. B. (2014). Cognitive Symptom Management and Rehabilitation Therapy (CogSMART) for veterans with traumatic brain injury: pilot randomized controlled trial. *Journal of Rehabilitation Research and Development*, 51(1), 59–70.
- Venville, A., Mealings, M., Ennals, P., Oates, J., Fossey, E., Douglas, J., & Bigby, C. (2016). Supporting Students with Invisible Disabilities: A Scoping Review of Postsecondary Education for Students with Mental Illness or an Acquired Brain Injury. *International Journal of Disability, Development and Education*, 63(6), 571–592.
- von Mensenkampff, B., Ward, M., Kelly, G., Cadogan, S., Fawsit, F., & Lowe, N. (2015). The value of normalization: Group therapy for individuals with brain injury. *Brain Injury: [BI]*, 29(11), 1292–1299.
- West, M. D. (1995). Aspects of the workplace and return to work for persons with brain injury in supported employment. *Brain Injury: [BI]*, 9(3), 301–313.
- Wilson, B. A., Gracey, F., Evans, J. J., & Bateman, A. (2009). *Neuropsychological Rehabilitation: Theory, Models, Therapy and Outcome*. Cambridge University Press.
- Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., Deruyter, F., Eng, J. J., Fisher, B., Harvey, R. L., Lang, C. E., MacKay-Lyons, M., Ottenbacher, K. J., Pugh, S., Reeves, M. J., Richards, L. G., Stiers, W.,

Zorowitz, R. D., & American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, Council on Clinical Cardiology, and Council on Quality of Care and Outcomes Research. (2016). Guidelines for Adult Stroke Rehabilitation and Recovery: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke; a Journal of Cerebral Circulation*, 47(6), e98–e169.

World Health Organization. (2006). *Neurological Disorders: Public Health Challenges*. World Health Organization.

Zellmer, A. (2015). *Life With a Traumatic Brain Injury: Finding the Road Back to Normal*. Fuzion Print.

ANEXOS

Anexo 1. Dificultades invisibles y experiencia subjetiva.

Tipo de Dificultad	¿Cómo se vive?
<i>Dificultades Cognitivas</i>	
Cansancio	"[...] un peso que me acompaña que a veces es más intenso y otras menos con el que estoy aprendiendo a convivir [...] Cuando este cansancio se instala, bloquea mi capacidad mental, ahora más limitada, ya que tengo una cantidad de energía menor que necesito repartir muy bien. Este cansancio pide al cuerpo y a la mente descansar, incluso dormir" (p. 30).
Dificultades de Atención	"[...] no era capaz de atender a una conversación cuando había más de dos personas en una habitación o un ruido externo [...] para mí, atender a cualquiera de estas pequeñas cosas me suponía tal esfuerzo que, muchas veces, desconectaba y no atendía a ninguna de ellas o directamente me quedaba dormida porque la situación me agotaba" (p. 41).
Lentitud de Pensamiento y Aprendizaje	"[...] se manifiesta sobre todo en el tiempo de reacción y, a veces, la conciencia de este tiempo lento me lleva a un estado de frustración que puede provocar tanto apatía como reacciones explosivas" (p. 63). "[...] ahora tengo un «disco duro» más pequeño a causa del TCE, aún sigo aprendiendo cosas nuevas, más lentamente y con algo más de esfuerzo" (p. 105).
Dificultades para Organizar	"[...] desorganización interna que se manifiesta a diario en la desorganización externa [...] Se ha traducido en la necesidad, casi diaria, de una persona que me ayude a organizarme en las actividades de la vida cotidiana [...] He conseguido mucha autonomía, pero aun así no puedo prescindir de esta ayuda" (p. 67).
Dificultades de Memoria	"Hay algunas cosas que no recuerdo (por suerte, lo importante lo recuerdo) y los recuerdos que conservo están muchas veces desordenados [...] me doy cuenta de las grandes dificultades que suponen las limitaciones serias de memoria para retomar la vida diaria y la vida social" (p. 89).
<i>Dificultades Conductuales</i>	
Impulsividad e Incontinencia Verbal	"En infinidad de ocasiones no consigo contenerme verbalmente. Mi impulsividad hace que diga cosas que no debería ni quería decir, aunque las piense [...] Es como si, debido a esta impulsividad, hubiera retrocedido en habilidades sociales" (p. 128).
Tendencia a la Pasividad	"Tengo una gran falta de iniciativa para empezar el movimiento. Siento como si no tuviera un motor interno; el motor tiene que venir de fuera, con horarios y obligaciones. Dejo de hacer muchas cosas por esta falta de impulso y luego me siento fatal por no haber aprovechado el tiempo" (p. 131).
<i>Dificultades Emocionales</i>	
Aplanamiento Afectivo o Inexpresividad Emocional	"La desconexión de las emociones es otra secuela que he ido descubriendo en los primeros meses, sufría una especie de anestesia afectiva [...] Me costaba entender, incluso, las emociones de mis hijos, mucho más las de otras personas, difícilmente podía ponerme en su lugar [...] Poco a poco y con mucho trabajo psicoterapéutico y neuro-funcional he conseguido volver a sentir las emociones, tal vez con menor intensidad (p. 142).
<i>Dificultades Físicas</i>	
Alteración Conciencia y Sensibilidad Corporal	"[...] bastante dificultad para tomar conciencia de mi cuerpo [...] Después de mucho esfuerzo consigo sentir un poco la parte izquierda de mi cuerpo y tengo la sensación de estar más apoyada en ese lado [...] siento como si el eje de mi cuerpo estuviera torcido" (p. 150).
<i>Dificultades de Identidad</i>	
Adaptación a Largo Plazo del Daño Cerebral	"el proceso de aceptación tras un cambio vital tan súbito no es fácil ni rápido. Por el contrario, he aprendido que este proceso nos acompaña durante mucho tiempo, nunca se detiene y lentamente se va consolidando a lo largo de los años. El grado de aceptación de los cambios está muy relacionado con la conciencia de nuestros déficits [...]" (p. 175).

Integración del Nuevo Yo y Conciencia de Déficit	“Después de una lesión cerebral, la identidad se altera (...) Aceptar la nueva situación vital y adaptarse a ella es además extremadamente complicado, ya que después de una lesión cerebral las personas no detectamos claramente qué cambios han ocurrido (...) el problema de la conciencia de los déficits es inseparable de la tarea de reconstruir nuestra identidad” (p. 178).
Interiorización de Herramientas Compensatorias	“[...] mi sensación de mejoría no tiene que ver con una disminución del daño cerebral adquirido o recuperación de funciones, sino con el uso sistemático de herramientas que me ayudan a lidiar con las dificultades del día a día (...) He encontrado mi nuevo «lugar en el mundo» y lo quiero consolidar. Y amar mi nueva identidad supone asumir que necesito mis herramientas, mis «muletas cognitivas», físicas y emocionales, para lidiar exitosamente con las exigencias (...) las necesito para conseguir los objetivos que deseo, para ser quien quiero ser” (p. 192 – 193).

Anexo 1. Dificultades invisibles y experiencia subjetiva.

Esta tabla muestra la experiencia subjetiva descrita por Aurora Lassaletta sobre las dificultades invisibles que ha experimentado como consecuencia del traumatismo encéfalo craneano que sufrió en el año 2005. Estas dificultades son descritas en su libro “El Daño Cerebral Invisible: Alteraciones cognitivas en TCE, ictus y otras lesiones cerebrales” (2017).

Anexo 2. Código de Búsqueda (Web of Science).

Número de búsqueda	Código de Búsqueda
1	(ALL={invisible brain injury}) AND ALL={acquired brain injury}
2	(ALL={invisible brain injury}) AND ALL={brain injury}
3	(ALL={invisible cognitive disability}) AND ALL={acquired brain injury}
4	(ALL={invisible cognitive disability}) AND ALL={brain injury}
5	((ALL={psychoeducation}) AND ALL={invisible brain injury}) AND ALL={acquired brain injury}
6	((ALL={psychoeducation}) AND ALL={acquired brain injury})
7	((ALL={psychoeducation}) AND ALL={brain injury})

La estrategia de búsqueda se adaptó a los requerimientos formales de cada base de datos, sin embargo, la configuración del código de búsqueda (operadores booleanos y campos de búsqueda), al igual que los términos clave fueron iguales en todas las bases de datos utilizadas. Como ejemplo, se detalla la estrategia de búsqueda implementada en la base de datos Web of Science (WoS).

PSYCHOLOGICAL CARE OF PERSONS WITH PARKINSON'S DISEASE: NEUROPSYCHOLOGICAL AND JUNGIAN PERSPECTIVES

ATENCIÓN PSICOLÓGICA A PERSONAS CON ENFERMEDAD DE PARKINSON: PERSPECTIVAS NEUROPSICOLÓGICAS Y JUNGUIANAS

+GEORGE P. PRIGATANO, PHD.*¹, BRITTANY WALLS, PHD.¹ Y TIFFANY M. MEITES, PHD.¹

*** Correspondence:**
George P. Prigatano
george.prigatano@commonspirit.org

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Parkinson's disease (PD) is a neurodegenerative disorder associated with progressive physical, cognitive, and emotional impairments. Providing psychological care for these individuals is an important part of their overall medical care and can be guided by experiences obtained from the broad field of neuropsychological rehabilitation. We summarize how the stage of the illness relates to disturbances in functional independence and executive functioning that negatively impact social integration and produces a fertile ground for depression and loss of hope. It is proposed that integrating knowledge from the neurosciences (especially neuropsychology) with psychodynamic insights (especially those of C.G. Jung) of the person with PD can play an important role in sustaining their resiliency and, in so doing, provides clinically relevant psychological care.

Keywords: Parkinson's disease, resiliency, neuropsychology, psychological care, psychodynamic observations, Jungian theory

La enfermedad de Parkinson (EP) es un trastorno neurodegenerativo que se asocia a deterioro físico, cognitivo y emocional progresivo. Proporcionar atención psicológica a estas personas es una parte importante de su atención médica general y puede guiarse por las experiencias obtenidas en el amplio campo de la rehabilitación neuropsicológica. Se resume cómo la etapa de la enfermedad se relaciona con las alteraciones de la independencia funcional y del funcionamiento ejecutivo, que impactan negativamente en la integración social y producen un terreno fértil para la depresión y la pérdida de esperanza. Se propone que integrar los conocimientos de las neurociencias (especialmente la neuropsicología) con los conocimientos psicodinámicos (especialmente los de C.G. Jung) de la persona con EP puede desempeñar un papel importante en la mantención de su resiliencia y, al hacerlo, proporciona una atención psicológica clínicamente relevante.

Palabras claves: Enfermedad de Parkinson, resiliencia, neuropsicología, atención psicológica, observaciones psicodinámicas, teoría junguiana

¹Department of Clinical Neuropsychology, Barrow Neurological Institute at St. Joseph's Hospital and Medical Center, Phoenix, Arizona, Estados Unidos

INTRODUCTION

Neuropsychological rehabilitation includes a broad array of interventions aimed at recovery and/or compensation of the disturbances in higher integrative brain functions that are directly or indirectly associated with underlying brain dysfunction (Prigatano, 2002). While the field of neuropsychological rehabilitation is entering a new era in which objective evidence of changes in brain structure or functioning can be documented and correlated with changes in higher integrative neuropsychological functions (Prigatano, Braga, Johnson, & Souza, 2021), efforts at helping the person psychologically adjust to their limitations have remained a key feature of this form of care (Prigatano, 1999; Ben-Yishay & Diller, 2011). The psychological adjustment process often includes helping the person re-establish a meaningful life from their perspective. Jungian theory can facilitate this process in patients who have acquired a brain injury typically in their early to middle years of life (Prigatano, 2012).

There are a growing number of patients, however, who are older and who have a progressive neurodegenerative disorder. They typically do not receive classic neuropsychological rehabilitation services. However, they also struggle with the effects of impaired cognitive functioning, disturbance of their relationships with important people in their life, and a loss of hope in light of their progressive physical dependence on others. Can any of the activities provided in neuropsychological rehabilitation be included in their care that meaningfully helps them?

Influenced by the insights of Carl Jung (1957), it has been suggested that neuropsychological rehabilitation often "...includes efforts to help the person relate to various symbols in their life that reflects long standing conscious and unconscious strivings unique to their individuality." (Prigatano, 2022). When this is successfully done, psychological adjustment to even neurodegenerative disorders can be improved. This paper attempts to describe a clinical approach that integrates knowledge of the neurological and neuropsychological consequences of Parkinson's disease with psychodynamic insights to substantially aid psychological care for persons with late stage Parkinson's disease.

PARKINSON'S DISEASE AND ITS STAGES OF DECLINE

Parkinson's disease (PD) is a neurodegenerative disorder characterized by both motor and non-motor (i.e. cognitive and affective) disturbances (Tröster, 2015). The neuropathology

underlying this disorder has attracted considerable scientific attention; several reviews on this topic are available (e.g. Cudaback et al., 2015). As a progressive disorder, the person's ability to speak, move, stand and walk safely is diminished over time, as are various cognitive functions (Tröster, 2015). Considerable work has gone into studying how activities of daily living are influenced by the stage of the disease.

One commonly used scale which describes the various stages of PD is the Hoehn and Yahr (1967) scale. During the initial stages of the disease (Hoehn and Yahr Stage 1), motor symptoms (e.g., tremor, rigidity, bradykinesia) are unilateral with minimal to no impairment in activities of daily living (ADLs). Hoehn & Yahr Stage 2 is characterized by bilateral involvement of motor symptoms, and daily tasks become increasingly difficult and lengthy. Limitations with ADLs early in the disease course may be circumvented with the use of compensatory strategies (e.g., allowing extra time to perform ADLs or redefining roles so that the task is no longer necessary for the patient) (Hariz & Forsgren, 2010). The transition from Hoehn & Yahr stage 2 to 3 is associated with the emergence of postural instability indicating moderate disease. During this stage, however, patients typically remain physically independent (Hoehn & Yahr, 1967), but mild cognitive impairments are frequently present. At Hoehn & Yahr stage 4, the patient has severe disability, with frequent falls and increased cognitive decline. Finally, by Hoehn & Yahr stage 5, the patient requires a wheelchair for mobility and is frequently described as having dementia (Hoehn & Yahr, 1967; Hawkes, Tredici, & Braak, 2009).

Among the motor symptoms, gait impairment, postural instability, and bradykinesia have the strongest association with level of disability (Shulman, 2010). Challenges with ADLs appear dependent on the subtype of the disease (i.e., tremor predominant vs. postural instability/gait difficulty (PIGD) (Hariz & Forsgren, 2010)). For example, in a community-based study examining ADLs and quality of life, patients with the PIGD subtype had significantly greater difficulty with both basic and instrumental ADLs compared to patients with the tremor predominant subtype (Hariz & Forsgren, 2010).

Persons with PD can present with a spectrum of cognitive disorders, even in the early stages of the disease (Schmand & Tröster, 2015). Disorders of executive function are often present and include difficulties initiating and organizing various projects in a timely fashion, as well as maintaining working memory capacity. This latter capacity can play a special

role in prospective memory. Clinically it often appears that failures in prospective memory erode the person's self-confidence and make them more emotionally dependent on others with a tendency to later avoid social contact.

A combination of physical limitations and cognitive impairments have been linked to decreased social interactions and substantially reduced quality of life (Rahman, Griffin, Quinn and Jahanshahi, 2008). With these changes, depression can become a central feature of PD.

DEPRESSION AND THE LOSS OF HOPE IN PARKINSON'S DISEASE

Depression is a disorder of mood. Given that only five symptoms are required to meet diagnostic criteria, individuals with major depression can present with varied symptoms. Common symptoms or indications of depression include physical complaints (e.g., low energy levels), vegetative complaints (e.g., disturbances of sleep and appetite), cognitive complaints (e.g., poor concentration and difficulty making decisions), as well as dysphoric mood per se (e.g., excessive pessimism or guilt, failure to enjoy once pleasurable activities, and loss of hope) (DSM-V, 2013). Given the variety of potential symptoms associated with depression, estimates of the prevalence of depression in persons with PD can vary greatly. Generally speaking, however, it is not uncommon to find estimates to be about 50% for persons with PD (Yamanishi et al, 2013; Marsh & Dobkin, 2015). There is often not a linear relationship between the level of physical disability associated with PD and the presence and severity of depression (e.g., van der Hoek et al., 2011). However there tends to be a more direct relationship between the severity of physical limitations and quality of life (e.g. Weintraub et al., 2004). Depression and quality of life are closely related but can be viewed as independent but overlapping constructs (e.g. Kuhlman et al. 2019; Su et al., 2021), especially in persons with PD. From a psychological care perspective, building resiliency often reduces but does not necessarily eliminate depression (e.g. Robottom et al., 2012).

Cognitive-behavioral therapy (CBT) has received much attention as a treatment for depression in persons with PD (Hong et al., 2021; also see Marsh & Dobkin, 2015). When such treatment is applied, improvements in memory and executive functioning have been reported. Thus CBT may be especially helpful in dealing with the cognitive correlates (or symptoms) associated with depression. Depending on the nature of the dysphoric symptoms (e.g., excessive

guilt or loss of hope), other treatment modalities also may be helpful. For example, talking about the sources of guilty feelings within the context of a trusting therapeutic relationship or aiding in the management of a "hopeless issue" in a person's life via psychodynamic psychotherapy can also be helpful (see Prigatano, 2020).

BUILDING RESILIENCY IN PERSONS WITH PARKINSON'S DISEASE

Resiliency and its correlates have been a topic of interest in both the psychodynamic literature (Fontagy et al., 1994) and in the neurosciences (Southwick & Charney, 2012). The neuroscience literature often emphasizes the role of "environmental stressors and genetic predisposition" as significant contributors to reduced resiliency. Psychodynamic theorists often emphasize the important role of secure child-parent attachments or "bonding" (Bowlby, 1969), which help maintain resiliency at different stages of life. There are interesting life stories that lend support to the importance of the person's attachment history and their ability to either effectively deal with the motor and cognitive consequences of a neurological disorder later in life (Douglas, 2002) or to ineffectively deal with those consequences (Pollak, 1998). Well-designed longitudinal studies on "normal" human aging (Vaillant, 2003), however, reveal that "aging well" (which implies good resiliency and a reduction of psychological distress during the aging process) is a more complicated story. Several factors may contribute to a person's capacity to be resilient when faced with losses. Some of the findings are paradoxical. For example, having a supportive loving relationship with the primary caregiver is often associated with "aging well", but not always. Some individuals are able to build loving supportive relationships later in life that seem to contribute to sustained resiliency.

Contributing factors perhaps can be best identified when a definition of resiliency is provided. For the purposes of this paper, "... resiliency is the capacity within a person that helps the individual deal with adversity in life in an adaptive manner that, in turn, leads to greater functional achievements and increased sense of self-efficacy with associated joy" (Prigatano, 2020, pg. 490). This definition emphasizes that, by increasing or maintaining resiliency, the person will not only adapt better to an underlying illness and associated disabilities but will also experience less psychological distress and more frequent joyful experiences associated with increased self-efficacy.

While there is no single way of approaching the task of psychologically helping persons with Parkinson's disease maintain and/or rebuild their resiliency in the face of a progressive neurodegenerative disease, understanding the individuality of a person and their process of individuation as C.G. Jung (1957) described it is one helpful approach.

INDIVIDUALITY, INDIVIDUATION AND NEUROLOGICAL AND NEUROPSYCHOLOGICAL IMPAIRMENTS

Jung employed two concepts when working with non-neurological patients in psychotherapy that are relevant to the psychological care of persons with PD. The first concept was that of "individuality." Individuality refers to the unique characteristics and life history of the person. It includes, of course, their genetically determined features (i.e. skin color, height, facial features, temperament, etc.) as well as their early life experiences, including the quality of their child care, the type and quality of their education, their occupational and marital history, their primary language, and their cultural background (which includes their philosophy of life and religious orientation). Providing psychological care for any person requires never forgetting about these important individual features when talking (or interacting) with them about their struggles in life. What is said and done must always be in line with their unique history. That is why there is no "one way" to provide psychological help. Jung often emphasized, for example, psychotherapy with a Catholic, Mormon, Hindu etc. should be conducted in the context of respecting (not attempting to change) their religious beliefs. Jung felt knowing the symbols that consciously or unconsciously guide the person's life activities was often key to helping deal with stressful issues in their life. These symbols are often reflected in the patient's favorite stories, movies, and songs, as well as in dream material.

Keeping in mind this basic approach, another factor is crucial. As the clinician begins to know the person they are attempting to psychologically help, they must also obtain a reasonable understanding of the level of individuation the person achieved at the time their neurological disorder began to affect their life. This knowledge helps the provider better understand the adaptive and non-adaptive decisions the individual has made prior to seeking out psychological consultation. It helps prepare the psychological clinician to approach the person in a manner that helps facilitate the therapeutic relationship.

In his extensive psychotherapeutic work, C.G. Jung (1957) noted that human beings have the yearning to become "who

they really are." This yearning is not a self-centered, childish ambition. It is the process of "individuation," which is the goal of normal psychological development and is crucial for a successful adaptation to life per Jung. He states: "individuation has two principal aspects: in the first place it is an internal and subjective process of integration and in the second it is an equally indispensable process of objective relationship" (pg.234). These are important insights that are very relevant to the psychological care of persons with an underlying neurological disorder. To the degree to which an individual can integrate the various aspects of their personality (e.g. "conscious and unconscious" features and "the positive and negative features"), they have a better internal sense of who they are and what other people go through in life. This concept is not too far removed from Eric Erikson's concept of "ego integrity" (Erikson & Erikson, 1997).

The second important accomplishment of the process of individuation is that it allows for the development of "objective relationships." That is, the person is now less likely to have a distorted view of who they are and who others are in their life. Others are not just a means by which the person's needs are met. It is recognized that others have their own needs and personality. One can better relate to the "other person" in a more just and reality based manner. This, by its nature, tends to foster at least a positive connection with others and at best a loving bond with others, which is perhaps the most satisfying of all life's experiences. It is the basis of restoring hope and trust during times of decline in functioning, to use Eric Erikson's terminology (see Erikson & Erikson, 1997).

While building or maintaining resiliency in persons with PD is guided by knowledge of both their individuality and the level of individuation achieved at the time that PD onset occurred and its present stage, it is also dependent on understanding how the neurological and neuropsychological disturbances are affecting the person in "real life."

While neurologists can help the patient better understand and manage their motor symptoms and associated physical disabilities, clinical neuropsychologists can help the patient better understand and manage their cognitive and affective symptoms. Given the variability of cognitive impairments associated with PD, a complete examination is often necessary to clarify how the disease appears to be affecting the person's cognitive functioning in everyday life. This is not always obvious to the patient or family member; obtaining this information often can in itself provide insight

and reassurance. Monitoring the patient's neuropsychological status over time further helps the patient and family understand the nature of the progressive difficulties the person experience in everyday life. This commitment to follow the patient and to participate in their care helps foster a therapeutic bond between the psychologist, the patient, and their significant other. This bond (or therapeutic relationship) can help the patient and family members accept guidance in the patient's clinical management when such guidance is needed. An example of this approach is illustrated in a previous publication (Prigatano, 2020, pg.260-268).

In assessing the neuropsychological characteristics of a person with PD, it is important to stay focused on what the patient experiences and what concerns them the most. For example, the patient may be upset with ongoing word finding problems when communicating with others. They may report getting lost in a thought and forgetting what needs to be done. They may not be aware of any unusual difficulties with balance or safety in walking. Yet their spouse may get frustrated with the fact that the patient does not seem to be aware of their risk for falls. Explaining that anosognosia for motor impairments is common in PD patients (Maier & Prigatano, 2017) and reassuring the patient that "getting lost" in their thoughts is a frequent subjective experience of some PD patients (most likely related to subtle but important frontal lobe dysfunction) gives the patient and their spouse a person they can turn to when dealing with new unpredictable cognitive and behavioral problems.

Each person with PD has their own unique pattern of neuropsychological strengths and weakness, and each have differences as it relates to their individuality, stage of individuation, and stage of PD. This clinical approach helps the clinical neuropsychologist be of maximal help to the patient and their families.

ILLUSTRATIVE VIGNETTES

A few brief clinical vignettes are provided to illustrate how this approach can help patients deal with specific psychological issues in light of their own individuality and level of individuation. These illustrative vignettes also incorporate knowledge regarding the patient's level of disability and neuropsychological characteristics. Informed consents to describe portions of their psychological care were obtained by the patient or their surviving spouse.

A successful elderly gentleman noticed a tendency to forget to remember things he must do (i.e. a decline in

prospective memory). He also noticed more difficulty doing simple math (i.e. the beginnings of dyscalculia), something he excelled at in the past. These experiences occurred around the time he was developing "unsteady gait" and reduced dexterity (see Prigatano, 2020, pg.393). At this phase in his illness, his diagnosis was not established; in hindsight he would be classified as being between stages 1-2 on the Hoehn and Yahr (1967) scale.

He was concerned about these changes but had grown-up in an environment that fostered self-reliance and "keeping one's problems to oneself." His wife eventually encouraged (i.e. convinced) him to reluctantly undergo a neuropsychological examination. He underwent psychometric testing as a part of the examination and listened to what the clinical neuropsychologist said about his functioning. That was all very interesting, but he wanted practical statements about what his diagnosis was and what if anything could be done about it.

The clinical neuropsychologist described the patient's neurocognitive limitations and his strengths. He recognized the man's good intelligence despite his emerging memory and calculation deficits. The clinical neuropsychologist emphasized the limits of the examination findings at that time for arriving at a diagnosis and noted that, without a clear diagnosis, specific treatment recommendations would be premature. The patient, a "no nonsense individual," appreciated that honesty. He liked how the clinical neuropsychologist talked to him about the findings. As they talked further, they found that they had common areas of interest, and the patient now stated he would be willing to come back for repeat examinations to help with his diagnosis. He wasn't that interested in testing, but he wanted to continue to talk to the clinical neuropsychologist because he could relate to him.

Over the next three year period of time, in which his motor and cognitive functioning worsened to stages 2-3 on the Hoehn & Yahr (1967) scale, the person began to talk about feeling useless. Not only did he have worsening tremor, but he had difficulty walking and was unsteady in his gait. He began to have frequent falls. He became progressively socially isolated. He wanted to die, and he wanted the neuropsychologist to know about that feeling.

A guiding "symbol" in his life was to not waste anything and to be helpful to others. Thus he wanted to make arrangements to be an organ donor at the time of his death. He was reassured this would happen by his wife. This gave him some momentary relief and will to persist.

As the psychotherapeutic relationship evolved (by this time he was at a Hoehn & Yahr stage 4), he was able to talk about two things that were bothering him during his adult life. As a result, he struggled with periodic guilt feelings. His individuation process (of which he was only partially aware) included repeated efforts to make people smile and laugh, since there were times in his life in which he felt he caused others to be hurt by his actions. This was acknowledged, and it was noted by the clinical neuropsychologist involved in his care that most people, later in life, reflect on things they have done in the past that they wish they had not done. The patient was quiet after this statement was made and acknowledged the truth of the statement.

In the very last stages of the illness (Stages 4-5) he had the continued need to make people smile as an ongoing feature of his individuation process. Even when he could no longer speak in an intelligible fashion, he would hand out small pieces of candy to strangers to bring a smile on their face. The clinical neuropsychologist recognized with him his special ability to make others smile. Giving out "this piece of candy" was "a symbol" of who this man had always been in his adult life despite his severely declining cognitive and physical functioning. It helped him sustain his resiliency as reflected by his willingness to repeatedly come into the psychologist's office to discuss what was happening in his life up until his death.

Another example of the importance of symbols, that help define the individuality of person with PD, was seen in an elderly gentleman who was the recipient of racial prejudice during his life. He entered a profession to combat injustice in its various forms. Even though he could not stand or walk independently, his "voice" (in the symbolic sense) needed to be heard. Many psychotherapy sessions were spent talking about local and world politics and his views about trying to correct injustice issues. This type of dialogue helped him sustain his sense of respect and preserve his individuality. He repeatedly stated how much he enjoyed these conversations despite his declining functional status. It contributed to a resilient attitude even in the presence of moderate depression and becoming eventually bedridden. When he was initially seen, he was at Hoehn & Yahr (1967) stage 1 and now is at stage 4.

A third example was an elderly man who was initially seen when he was at Hoehn & Yahr stage 2 and followed until his death at stage 5. Amongst his cognitive difficulties was a severe working memory impairment. He literally could not remember what he was just saying as he approached the last 6 months of his life. He did not know how to explain this

problem to his wife. When the clinical neuropsychologist tracked his performance on various working memory tasks, there was now "objective" evidence that a severe decline in working memory had taken place. The patient was relieved with this information and was very eager that it be explained to his wife.

He was often worried that his wife felt that he could do better if he was motivated to do so. Why was this such a recurring theme in his life? The patient was able to privately confide (after getting to know him as a person) that his mother always seemed displeased with him, and she felt he could do better if he tried. Given these early life experiences, the patient worked very hard to become quite accomplished and financially independent. He progressively recognized that he was responding to his wife in a manner similar to how he had responded to his mother when he perceived that he had performed in a manner that displeased her. This was clearly a reflection of his individuality and an ongoing feature of his process of individuation.

Since he no longer could verbally explain to his wife that he was doing the best that he could, having the clinical neuropsychologist explain his cognitive limitations produced considerable psychological relief for him up until his death.

SUMMARY

This brief paper attempted to describe an approach to the psychological care of persons with PD which integrates an understanding of the patient's neurological, neuropsychological and psychodynamic features when helping them sustain (and perhaps build) their resiliency when faced with the devastating consequences of a neurodegenerative brain disorder. Jungian insights can be quite helpful in this process. We have also briefly considered the role of understanding factors that are correlated with resiliency in persons with PD and have summarized some of the major challenges that these patients face during the various stages of their illness.

REFERENCES

- Ben-Yishay, Y., & Diller, L. (2011). *Handbook of holistic neuropsychological rehabilitation: outpatient rehabilitation of traumatic brain injury*. Oxford University Press, New York, NY.
- Bowlby, J. (1969). Attachment and loss: volume I: attachment. In *Attachment and Loss: Volume I: Attachment* (pp. 1-401). London: The Hogarth Press and the Institute of Psycho-Analysis.
- Cudaback, E., Cholerton, B. A., Montine, K. S., & Thomas, J. (2015). Neuropathology, Biomarkers, and Cognition in Parkinson's. In A. I Tröster (Ed.) *Clinical Neuropsychology and Cognitive Neurology of Parkinson's Disease and Other Movement Disorders*. [pp 129-147]. Oxford University Press, New York, NY.
- Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (2013), American Psychiatric Association, Arlington, VA
- Douglas, K. (2002). *My stroke of luck*. Morrow Publisher, New York, NY.
- Erikson, E.K. & Erikson J.M. (1997) *The Life Cycle Completed*, W.W. Norton & Company, NY.
- Fonagy, P., Steele, M., Steele, H., Higgitt, A., & Target, M. (1994). The Emanuel Miller memorial lecture 1992 the theory and practice of resilience. *Journal of Child Psychology and Psychiatry*, 35(2), 231-257. doi.org/10.1111/j.1469-7610.1994.tb01160.x
- Hariz, G. M., & Forsgren, L. (2011). Activities of daily living and quality of life in persons with newly diagnosed Parkinson's disease according to subtype of disease, and in comparison to healthy controls. *Acta Neurologica Scandinavica*, 123(1), 20-27. DOI: 10.1111/j.1600-0404.2010.01344.x
- Hawkes, C. H., Del Tredici, K., & Braak, H. (2010). A timeline for Parkinson's disease. *Parkinsonism & related disorders*, 16(2), 79-84.
- Hoehn M, Yahr, M. (1968) Parkinsonism: onset, progression and mortality. *Neurology*, 17, 153-63. DOI: 10.1212/wnl.17.5.427. DOI: 10.1016/j.parkreldis.2009.08.007
- Hong, C.T., Tan, S., & Huang, T.W. (2021). Psychotherapy for the treatment of anxiety and depression in patients with Parkinson disease: A meta-analysis of randomized controlled trials. *Journal of the American Medical Directors Association*, 22, 2289-2295.
- Jung, C. G. (1957) *Practice of Psychotherapy: Essays on the Psychology of the Transference and other Subjects*. Princeton University, Princeton, NJ.
- Maier, F., & Prigatano, G. P. (2017). Impaired self-awareness of motor disturbances in Parkinson's disease. *Archives of Clinical Neuropsychology*, 32(7), 802-809.
- Marsh, L., & Dobkin, R. D. (2015). Depression and anxiety in Parkinson's disease. In A.I.Tröster (Ed.) *Clinical Neuropsychology and Cognitive Parkinson's Disease and Other Movement Disorders*, [pp 265-290]. Oxford University Press, New York, NY.
- Pollak, R. (1998). *The creation of doctor B: A biography of Bruno Bettelheim*. Simon and Schuster, New York, NY.
- Prigatano, G. P. (1999). *Principles of neuropsychological rehabilitation*. Oxford University Press, New York, NY.
- Prigatano, G. P. (2002). Holistic neuropsychological rehabilitation and models of change after brain injury. In WH Brouwer, AH van Zomeren, IJ Berg, JM Bouma & EHF de Haan (pp 53-69), *Cognitive rehabilitation: a clinical neuropsychological approach*. Boom Publishers, Amsterdam.
- Prigatano, G. P. (2012). Jungian contributions to successful neuropsychological rehabilitation. *Neuropsychoanalysis*, 14(2), 175-185.
- Prigatano, G. P. (2020). *Clinical neuropsychology and the psychological care of persons with brain disorders*. Oxford University Press, New York, NY.
- Prigatano, G. P., Braga, L., Flores Johnson, S., & Souza, L. (2021). Neuropsychological rehabilitation, neuroimaging and neuroplasticity: A clinical commentary. *NeuroRehabilitation*, 49, 255-265
- Prigatano, G. (2022). Leonard Diller and Yehuda Ben-Yishay's Contributions to Neuropsychological Rehabilitation:

A Commentary with Personal Reflections. *Archives of Clinical Neuropsychology*, 37(3), 722-727.

symptoms on disability in Parkinson's disease. *Journal of the American Geriatrics Society*, 52, 784-788.

Rahman, S., Griffin, H. J., Quinn, N. P., & Jahanshahi, M. (2008). The factors that induce or overcome freezing of gait in Parkinson's disease. *Behavioural Neurology*, 19(3), 127-136.

Yamanishi, T., Tachibana, H., Oguru, M., Matsui, K., Toda, K., Okuda, B., & Oka, N. (2013). Anxiety and depression in patients with Parkinson's disease. *Internal Medicine*, 52, 539-545.

Robottom, B.J., Gruber-Baldini, A.L., Anderson, K.E., Reich, S.G., Fishman, P.S., Weiner, W.J., & Schulman, L.M. (2012). What determines resilience in patients with Parkinson's disease? *Parkinsonism and Related Disorders*, 18, 174-177.

Schmand, B., & Tröster, A. I. (2015). Earliest cognitive changes and mild cognitive impairment in Parkinson's disease. In A.I Tröster (Ed.) *Clinical Neuropsychology and Cognitive Neurology of Parkinson's Disease and Other Movement Disorders*, (pp. 205-238). Oxford University Press, New York, NY.

Shulman, L. M. (2010). Understanding disability in Parkinson's disease. *Movement Disorders*, 25(S1), S131-S135.

Southwick, S. M., & Charney, D. S. (2012). The science of resilience: implications for the prevention and treatment of depression. *Science*, 338(6103), 79-82.

Su, W., Liu, H., Jiang, Y., Li, S., Jin, Y., Yan, C., & Chen, H. (2021). Correlation between depression and quality of life in patients with Parkinson's disease. *Clinical Neurology and Neurosurgery*, 202, 106523.

Tröster, A. I. (2015). *Clinical neuropsychology and cognitive neurology of Parkinson's disease and other movement disorders*. Oxford University Press, New York, NY.

Vaillant, G.E. (2003). *Aging Well*, Little, Brown & Company, Boston, MA.

van der Hoek, T.C., Bus, B.A.A., Matui, P., van der Marck, M., Esselink, R.A., & Tendolkar, I. (2011). Prevalence of depression in Parkinson's disease: Effects of disease stage, motor subtype, and gender. *Journal of the Neurological Sciences*, 310, 220-224.

Weintraub, D., Moberg, P.J., Duda, J.E., Katz, I.R., & Stern, M.B. (2004). Effect of psychiatric and other nonmotor

MENTALISATION ERRORS IN AN ACQUIRED BRAIN INJURY SAMPLE ON THE RECOGNITION OF FAUX PAS TEST

ERRORES DE MENTALIZACIÓN/TEORÍA DE LA MENTE EN UNA MUESTRA DE LESIÓN CEREBRAL ADQUIRIDA EN EL TEST DE RECONOCIMIENTO DE FAUX PAS

MAARTEN MILDERS¹, GILES YEATES*²

* Correspondencia:
Giles Yeates
m.v.milders@vu.nl

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Background: Mentalisation (also known as theory of mind) difficulties have been reliably demonstrated across different subtypes of adult acquired brain injury (ABI), and the role of such impairments in negative psychological and interpersonal outcomes for survivors and their significant others has been increasingly highlighted.

Aims & Methodology: This study aimed to characterise the most salient aspects of mentalising performance in a large ABI sample, relative to matched controls. The participants were 88 (64 male, 24 female) persons with acquired brain injuries (TBI; CVA; other subtypes) participating in community neuro-rehab services (mean age 45.2 years, SD 10.7; mean time since injury 6.69 years; range 1.5 – 31.3 years.) and 50 (34 male, and 16 female) healthy participants (mean age 45.3 years, SD 13.9). The main measure of mentalising operationalised in this study was the Recognition of Faux Pas Test (Stone et al., 2003), a story vignette task completed by patients and controls.

Results & Conclusions: Overall, the patient group made significantly more errors in detecting the presence of a faux pas than the matched control group ($t(132)=2.24$, $p<.05$, Cohen's $d = 0.4$), reflective of 1st order mentalising difficulties in the ABI group. However the patients did not make more errors than controls in explaining the reason for the faux pas ($p=.75$). Patterns in errors made by the patient group are explored, and implications for rehabilitation are discussed.

Keywords: Acquired Brain Injury, Theory of Mind, social cognition, Faux Pas, Neuropsychological Rehabilitation.

Antecedentes: Las dificultades de mentalización (también conocida como teoría de la mente, por sus siglas en inglés *ToM*) se han demostrado de forma fiable en diferentes subtipos de Lesión Cerebral Adquirida (LCA) en adultos, y se ha destacado cada vez más el papel de estas deficiencias en los resultados psicológicos e interpersonales negativos para los sobrevivientes y sus allegados.

Objetivos y metodología: El objetivo de este estudio es caracterizar los aspectos más destacados del rendimiento de la mentalización en una amplia muestra de LCA, en relación con controles emparejados. Los participantes fueron 88 (64 hombres, 24 mujeres) personas con lesiones cerebrales adquiridas (TEC, ACV, otros subtipos) que participaban en servicios de neurorrehabilitación de la comunidad (edad media 45.2 años, DE 10.7; tiempo medio desde la lesión 6.69 años; rango 1.5 - 31.3 años) y 50 (34 hombres y 16 mujeres) participantes sanos (edad media 45.3 años, DE 13.9). La principal medida de mentalización operacionalizada en este estudio fue el Test de Reconocimiento de Faux Pas (Stone et al., 2003), una tarea de historias en viñetas completada por pacientes y controles.

Resultados y conclusiones: En general, el grupo de pacientes cometió significativamente más errores en la detección de la presencia de un faux pas que el grupo de control emparejado ($t(132)=2.24$, $p<0.05$, d de Cohen = 0.4), lo que refleja las dificultades de mentalización de primer orden en el grupo de LCA. Sin embargo, los pacientes no cometieron más errores que los controles a la hora de explicar el motivo del faux pas ($p=0.75$). Se exploran los patrones de los errores cometidos por el grupo de pacientes y se discuten las implicaciones para la rehabilitación.

Palabras claves: Lesión cerebral adquirida, teoría de la mente, cognición social, faux pas, rehabilitación neuropsicológica

¹ Associate Professor, Faculty of Behavioural & Movement Sciences, Clinical Neuropsychology, Vrije Universiteit Amsterdam, Netherlands.

² Visiting Fellow, Centre for Movement, Occupational & Rehabilitation Sciences (MORes), Oxford Brookes University, UK.

INTRODUCTION

The ability to recognize and make inferences about other people's intentions and beliefs is often referred to as theory-of-mind (ToM) and this ability would be important for effective interpersonal communication. ToM as an ability is underpinned by a distributed neural substrate. A range of areas with the frontal and temporal lobes have been implicated (Frith & Frith, 2006; Samson et al., 2005) and dysfunctions in any of these areas could disrupt ToM (Adams, Schweitzer, Molenberghs & Henry, 2019). There are substantial interindividual differences in ToM and the ability can be disturbed in developmental disorders or impaired following brain damage (Channon & Crawford, 2000; Happé, Malhi, Checkley, 2001). Early research into ToM deficits focused primarily on developmental disorders, such as autism and Asperger's syndrome (e.g. Baron-Cohen, Leslie & Frith, 1986; Leekam & Perner, 1991), but there is also convincing evidence for acquired deficits in ToM following brain damage in adult patients, such as strokes or traumatic brain injury (e.g. Martin-Rodriguez & Leon-Carrion, 2010). Such difficulties in adult survivors of acquired brain injury have been associated with a range of negative psychosocial outcomes, including fewer relationships (Blonder, Pettigrew, & Kryscio, 2012), poorer community integration (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011), poorer relationships with work colleagues (Yeates et al., 2016) and poorer therapeutic working alliance with rehabilitation clinicians, thereby influencing rehabilitation outcome (Schönberger, Yeates & Hobbs, in press). Impairments in ToM and understanding intentions were also associated with social behaviour and behavioural changes following TBI, more severe impairments in ToM were associated with poorer social behaviour and social outcome (Milders, 2018; Struchen et al., 2011). Therefore, ToM ability following ABI can also be relevant for understanding the factors that contribute to changes in social behaviour post-injury and as potential target for rehabilitation in order to improve social outcome.

Assessment of ToM in adult patients requires different measures than those that had been developed for use in children. A popular test for adult ToM is the Faux Pas test (Stone et al., 1998), which consists of vignettes with or without someone saying something inappropriate due to a false belief. Each story vignette is usually followed by two questions pertaining to faux pas (FP) detection ("did someone say something that they shouldn't have said?...who?"),

one question inviting representations of the mental states of those affected by the FP, and related social norms ("why shouldn't they have said it?") and finally a question about the intentions of the protagonist who committed the FP ("why did they do it?"). A later version of the task also includes questions pertaining to the emotional states of characters and a clarification of the respondent's understanding of characters' false beliefs. There are additional questions that identify if basic levels of story comprehension have been met by respondents.

In an earlier study we found that patients with traumatic brain injury (TBI) performed significantly poorer relative to controls when explaining the reason for the faux pas, which required understanding or explaining the intentions and feelings of the characters (Milders et al., 2006). A quantitative review by Martin-Rodriguez and Leon-Carrion (2010) of studies into ToM in acquired brain injury published prior to 2008 identified 9 studies that used the Faux Pas and in all studies patients were significantly impaired (with an overall moderate to large effect size, Cohen's $d = .70$) compared to healthy controls. Sample sizes varied between 9 and 41 patients. Across the different studies a positive association was found between the presence of acquired brain injury and faux pas performance. Studies with larger proportion of patients with TBI tended to show larger effect sizes. In addition, the presence of frontal lesions and lesions in the right hemisphere was associated with larger effect sizes.

More recent studies using the Faux Pas Test have identified impairments in ToM in participants with different forms of acquired brain injury. Bivona et al. (2014), Geraci et al. (2010), McLellan et al. (2013) and Muller et al. (2010) reported impaired Faux Pas performance in patients with TBI relative to healthy controls. Patients with moderate to severe TBI (McLellan et al., 2013) or with lesions in the ventromedial frontal area were particularly impaired on the Faux Pas test (Geraci et al., 2010), although their sample was small ($n=11$). This finding was confirmed in a study in patients with penetrating head injury (Leopold et al., 2012) Patients with ventromedial prefrontal lesions were impaired on the Faux Pas test. Lee et al. (2010) also found impaired Faux Pas performance in patients with medial frontal lesions as a result of surgical tumour removal. ToM deficits have been identified using other measures in patients with temporal cortical lesions (Olson et al., 2007) and in mixed right hemisphere cerebro-vascular accidents, including both anterior and posterior infarcts (Happé et al., 1999). These findings

suggest that ToM impairment in adult patients, as assessed with the Faux Pas task are common in patients with varied forms of acquired brain damage that impact on the distributed neuro-anatomical substrate for ToM.

However, there are two key methodological limitations of previous research. Firstly, the sample size in individual studies was limited, with the number of patients in most studies lying below 30. Secondly, although ToM impairments were found with different etiologies of brain damage, comparison of etiology required comparison across studies, as each study typically included only patients with the same etiology. When comparison between different studies, there is a risk that other differences (e.g. in methods or analysis), could account for the etiology group differences. In addition, there is a conceptual confusion, reflected in measurement and scoring methodologies in previous studies using the Faux Pas test. The majority of researchers have used the total scores summed from all questions pertaining to the vignettes that contain an incident of faux pas. These vignettes each are followed by four to six sub-questions (depending on which version of the task is used) for respondents that actually assess different aspects of ToM/mentalising. These include questions relating to 1st order versus 2nd order mentalising representations. First order mentalising refers to beliefs and/or intentions of characters affected by the faux pas who are privy to different information within each story. Second order mentalising involves the intentions of the character committing the faux pas towards the other characters, given their incomplete knowledge/naïve position within the story. Additionally, there are questions that elicit epistemic representations (pertaining to others' knowledge, beliefs and/or intentions) versus affective representations (others' feelings and emotional states). In most studies using the Faux Pas test in these different representational types, and any differences in respondents' abilities towards each, were conflated within the faux pas total score. This confusion is significant for both theoretical and clinical reasons. In a rare exception to the aforementioned literature, Lee et al., (2010) found that responses on the question of each faux pas story concerning the motivation of the protagonist ("why did they do it?") discriminated patients with ventro-mesial versus dorso-lateral surgical lesions, with the former performing significantly worse on this question than the latter. This question type relates specifically to a respondent's ability to represent the intentions of the protagonist in each story, as

a function of the character's incomplete knowledge within the social situation (thereby requiring 2nd order representations – the character's beliefs about others' beliefs). Happé (1998) has highlighted the prevalence of deficits in 2nd order representations within her right hemisphere CVA adult sample, whereas other researchers have highlighted the importance of negative hostility bias in different samples of brain injury survivors' representations of others' intentions (Knox & Douglas, 2008; Neumann et al., 2015; Stone et al., 1998; 2003; Zupan et al., 2014).

Given the above findings, conflating the accuracy of different levels and types of mentalising representations in patients' responses may reduce sensitivity to important neuro-anatomical differences in mentalising functions and the pathology of such in different clinical groups. Furthermore, clinicians may be differentially focusing on different types of ToM representation in their social cognition/psychotherapy interventions with these clinical groups, depending on the goals/foci of the work concerned. As such, clinicians would benefit from a knowledge base that teases out these sub-abilities and their relevance to other clinical outcomes. The study reported here used the Faux Pas test on survivors with acquired brain injury due to different etiologies and matched healthy controls in what might be the largest patient sample to date. Importantly, alongside total scores, responses to different Faux Pas question types (and the different mentalising abilities to which they pertain) were scored separately, along with categorization of characteristics in the erroneous responses. The goal of the study was to use a finer level of discriminatory analysis and to compare response patterns in different etiologies and different lesion locations.

METHOD

Participants

The participants were 88 (64 male, 24 female) persons with acquired brain injuries (mean age 45.2 years, SD 10.7) and 50 (34 male, 16 female) healthy participants (mean age 45.3 years, SD 13.9). The patients were recruited through three community rehabilitation services in the United Kingdom (Community Head Injury Service, Aylesbury and two Momentum Skills services in Birmingham and Newcastle). Healthy participants were recruited from the general population to match the patients for age and proportion of males and females. The patients had suffered acquired brain injury, with different aetiologies: traumatic

brain injury (40), CVA (35), hypoxia (3), infection (5), tumour (1) or other (4). Information on lesion location was available for 72 patients, from acute clinical documentation of relevant neuro-imaging and was categorized as frontal (21), posterior (16), subcortical (9) or diffuse (24). Mean time since injury in the patient group was 6.69 years (range 1.5 – 31.3 years). All participants gave informed consent to take part in the study, which had been approved by the Oxfordshire Research Ethics Committee B.

Faux Pas task

Faux Pas Test (Stone et al., 1998). This test consists of 20 vignettes, 10 describing a social faux pas, 10 without faux pas. After participants are read each story, they answer a number of questions while keeping the story in front of them. The first question is whether someone had said something they should not have said? If question 1 is answered yes, three further questions are asked, 1. Who said something they should not have said? 2. Why should they not have said it? 3. Why do you think they said it? A final and fifth question to test the general understanding of the stories is asked, regardless of the answer to the first question. Following stories without faux pas, two questions are asked that assess detection of the (absence) of the faux pas and comprehension of the story (control question). Participants could receive 1 point on each question for a correct response and no points for an incorrect response. Faux Pas items were presented one-by-one and intermingled with items that did not contain a faux pas. The items were presented in a semi-random order. The items without faux pas were merely included to make participants aware that not all items contained a faux pas and responses to these items were not analysed further.

Verbal responses of the participants were recorded on the scoring sheet and scored following predetermined guidelines. If participants made an incorrect response, a distinction was made between different types of errors. First order errors were recorded if a participant failed to detect the presence of a faux pas (i.e. responding “no” to question 1) or provided an incorrect response to questions 2 or 3, which indicated a failure to understand that a faux pas had been made. Incorrect explanations of the reason for the faux pas (incorrect response to question 4), which indicated that the participant had not fully understood the faux pas arose from false belief, were further recorded as second order errors and subdivided into omission and commission

errors. In omission errors the explanation refers only to the intentions of the perpetrator of the faux pas, without referring to the recipient of the faux pas (e.g. he thought it was funny). In commission errors the explanation did refer to the recipient or person affected by the faux pas, but do not take into account the element of false belief or lack of information (e.g. he thought the joke would cheer everyone up.). The four categories of error scores (1st order, 2nd order total, 2nd order omission, 2nd order commission) were the main variables of faux pas performance that were compared between the participants groups. The responses were scored by two independent raters (MM and GY). Agreement between raters, based on a random sample of responses from 10 participants, was good ($r=0.83$).

RESULTS

Performance of the group of people with acquired brain injuries and the healthy control group on the 10 items containing a faux pas is displayed in Table 1. Performance is expressed as the number of errors detecting the presence of a faux pas (1st order errors), errors explaining the reason for the faux pas and the mental state of person making the faux pas in response to question 4 on each vignette (2nd order errors) and control scores representing general understanding of the story.

Overall, the patient group made significantly more errors in detecting the presence of a faux pas than the matched control group ($t(132)=2.24, p<.05$, Cohen's $d = 0.4$) but the patients did not make more errors than controls in explaining the reason for the faux pas ($p=.75$). Note that only when participants had correctly indicated the presence of a faux pas, they were asked to explain why they thought the faux pas had occurred. Because the number of detection errors was higher in the patient group, the number of explanations of faux pas that a participant made, was divided by the number of explanation questions that they had attempted. Comparing this proportion of explanation errors between the two groups again revealed no significant difference between the patients and controls ($p=.63$) (see Table 1).

Errors in explaining the reason for the faux pas were further subdivided into omission errors (not referring to the perpetrator attitude towards the recipient of the faux pas, only to the perpetrator's own intentions) and commission errors (including the perpetrator attitude towards the recipient of the faux pas, but not taking into account false belief or lack of information as an explanation for the faux pas).

The mean number of omission and commission errors in the two groups are shown in Table 1. Between- group comparisons showed no significant differences on either omission or commission errors ($p > .8$). Comparing the proportion of omission and commission errors divided by the number of times that the explanation questions had been attempted, also revealed no difference between the patient and control groups ($p > .66$).

General comprehension scores were very high in both the patient and the control group, but the patients made slightly more errors than controls, who made none ($t(134) = 2.25$, $p < .05$). Errors on the comprehension questions may indicate that the patients had not fully understood the vignette. If they had not fully understood the vignette, the errors on the questions concerning the faux pas may not reflect problems understanding intentions and false belief. In order to rule out that lack of understanding of the vignette resulted in errors on the faux pas related questions, the analyses were repeated including only those patients who made no errors on the comprehension question ($n = 74$). The results were comparable to those obtained with the full patient sample; the number of first order errors was higher in the patient group than in the controls, the difference being nearly significant ($t(120) = 1.94$; $p = .054$), but the number of second order errors was similar in the two groups, suggesting that even when comprehension of the vignettes was intact, detecting a faux pas was still poorer in the patient group than in the healthy comparison group.

The brain injured group contained a range of etiologies, the most frequent being traumatic brain injury (TBI) and stroke or cardiovascular accident (CVA). To examine whether etiology influenced performance on the faux pas test, the patient group was subdivided in a group of patients with TBI ($n = 40$) and a group of stroke patients ($n = 35$). Faux pas scores of these two subgroups are displayed in Table 2. Comparing Faux Pas performance in the TBI group and the CVA group showed no difference on any of the Faux Pas scores between the two groups.

For 72 of the brain injured patients information on lesion location was available. To examine whether location of the lesion influenced performance, regardless of aetiology, patients for whom lesion location was available were grouped into a group with predominately frontal lesions ($n = 21$), a group with posterior lesions ($n = 16$) and a third group with diffuse lesions ($n = 24$). Detection errors, explanation errors and scores on the control questions were compared between these three lesion groups (see Table 3). One-way ANOVA revealed no significant group differences on any of faux pas scores ($p > .49$). Lesion location in this sample had not significant effect on faux pas performance.

DISCUSSION

Patients with acquired brain injury were significantly poorer than healthy participants at detecting the presence of a faux pas. Contrary to expectation, explaining the reason for the faux pas, which requires understanding the intentions

Table 1. Performance on the faux pas test in the patient and control groups

	Patients with ABI (n=84)		Controls (n=50)		
	M	(SD)	M	(SD)	
1 st order errors: failure to detect presence of a faux pas (max = 20)	4.98*	(3.45)	3.48	(4.18)	
2 nd order errors: Errors explaining faux pas	3.82	(2.89)	3.94	(2.00)	
Proportion errors explaining faux pas	0.51	(0.28)	0.48	(0.23)	
Omission errors	2.68	(2.31)	2.74	(1.61)	
	Proportion omission errors	0.35	(0.28)	0.34	(0.21)
	Commission errors	1.14	(1.14)	1.20	(1.47)
	Proportion commission errors	0.15	(0.16)	0.14	(0.16)
Control question (number correct)	9.72*	(6.43)	10	0.0	

*Significantly different relative to healthy comparison group, $p < .05$

Table 2. Performance on the faux pas test in those patients who had suffered traumatic brain injury or stroke.

		Patients with TBI (n=40)		Patients with stroke (n=35)	
		M	(SD)	M	(SD)
1st order errors: Failure to detect presence of faux pas		5.26	(3.49)	4.45	(3.08)
2nd order errors: Errors explaining faux pas		4.13	(2.41)	3.45	(2.04)
Proportion errors explaining faux pas		0.55	(0.28)	0.45	(0.26)
	Omission errors	2.82	(2.44)	2.27	(2.02)
	Commission errors	1.31	(1.23)	1.18	(1.10)
Control question (number correct)		9.77	(0.67)	9.80	(0.58)

Table 3. Performance on the Faux Pas test in those patients with predominantly frontal lesions, posterior or subcortical lesions or diffuse lesions

		Frontal (n=21)		Posterior (n=16)		Diffuse (n=24)	
		M	(SD)	M	(SD)	M	(SD)
1st order errors: Failure to detect presence of faux pas		5.39	(2.99)	4.46	(3.44)	5.35	(4.59)
2nd order errors: Errors explaining faux pas		3.55	(2.30)	3.33	(2.19)	3.96	(2.36)
	Omission errors	2.34	(2.03)	2.00	(2.36)	2.91	(2.23)
	Commission errors	1.21	(1.35)	1.33	(0.72)	1.05	(1.18)
Control question (number correct)		9.87	(0.34)	9.67	(0.81)	9.74	(0.75)

of others and 2nd order mentalising representations, was not impaired in this patient sample. Overall, the patient group was impaired at recognizing the presence of a faux pas, suggesting that once they had detected the presence of a faux pas, the patients performed as well as healthy participants in explaining the faux pas, and on none of the error scores did the patients score more poorly than controls. The impairment in detecting the presence of a faux pas in the brain injury patients could not be explained by difficulties understanding the gist of the faux pas story. Even those patients whose performance on the question assessing general comprehension was flawless, performed more poorly than controls in detecting the presence of a faux pas. Within the group of patients, aetiology of the brain damage had little effect on performance. Patients with traumatic brain injury or CVA, by far the largest aetiology groups in this sample, performed very similar on the task. Suspected location of

the brain lesion also had little effect on faux pas recognition. Faux pas detection scores and error scores did not differ between subgroup of patients with predominantly frontal, posterior or diffuse lesions.

This study reported understanding of other people's intentions as tested using the Faux Pas test and relative to matched healthy controls in one of the largest samples of patients with acquired brain injuries to date. As expected, the results show poorer faux pas detection (requiring 1st order mentalising representations) in brain injured participants. Some studies have reported poor performance on the Faux Pas test in brain injured participants not in detecting the presence of a faux pas, but in explaining the faux pas or in 2nd order mentalising (Happe et al., 1998; Lee et al., 2014; Milders et al., 2006). However, most studies reported only total Faux Pas scores for their patient samples, without specifying the main source of errors. Based on the

findings of the current study, the main impairment might have been in detecting the presence of a faux pas. Previous studies found patients with prefrontal lesions to be more impaired on the Faux Pas test than patients with lesions in other regions (Geraci et al., 2010; Gregory et al., 2002; ; Leopold et al., 2012), whereas in the current sample performance in patients with frontal lesion did not differ from those with posterior or diffuse lesions. The cause of the brain injury also had no important impact on performance on the Faux Pas. Previous studies into the effect of brain injury on understanding intentions tended to include patients with a single aetiology (e.g. TBI or CVA). In the current study patients with TBI performed no different from patients who had suffered a CVA on the Faux Pas task. Together with the finding that lesion location had no impact on performance, the results of this study suggest that the presence of cortical lesions was the main factor for impairments on the Faux Pas test, rather than the exact location or the aetiology of the brain damage.

This conclusion is not in line with other studies that showed more severe impairments on the Faux Pas task in patients with frontal lesions, and in particular medial frontal lesions (Geraci et al., 2010; Lee et al., 2010; Leopold et al., 2012), or that impairments in patients with TBI tended to be more severe than in other forms of acquired brain injury (Martin-Rodriguez & Leon-Carrion, 2010). One of the limitations of the current study was that lesion location in the patient sample was typically based on CT scans, which may be less precise than the surgical lesions in study by Lee et al. (2010) or the localised lesion in the study by Leopold et al. (2012). We were not able to discriminate ventro-mesial and dorsolateral frontal lesions, an important distinction for some aspects of mentalising according to Lee et al., (2010). As a result, less precise lesion localization could have made it more difficult to identify a link between Faux Pas performance and lesion location in the current sample. On the other hand, mentalising and ToM abilities would rely on widespread brain networks (Adams et al., 2019; Frith & Frith, 2006), making it plausible that these abilities can be affected by lesions in various locations due to different aetiologies. Another limitation of the current study was that for the majority of participants with brain injury no information was available on severity of brain injury. As a result, it is unclear whether the pattern of impaired detection and correct explanation of faux pas was due to relatively mild brain injuries in the current sample and it is unclear how the current

sample compares to samples in previous studies that found Faux Pas impairments typically following moderate to severe brain injury. A further limitation of the study was that post-injury behaviour or changes in behaviour were not assessed in this sample. Although changes in behaviour following acquired brain injury are not rare (Baguley et al., 2006; Benedictus et al., 2010; Kelly et al., 2008) and impairments in understanding intentions and ToM are associated with post-injury behaviour (Milders, 2018; Struchen et al., 2011), the current study cannot confirm this link.

In sum, patients with acquired brain injury were impaired at detecting the presence of a faux pas, regardless of aetiology, but performed as well as healthy controls in explaining the reason the faux pas, which requires 2nd order mentalising. Mentalising in survivors of acquired brain injury has become a focus of rehabilitation intervention (Spikman et al., 2013), and has been shown to be a critical influence on the therapeutic working relationship between survivors and clinicians, irrespective of the rehabilitation goal (Schönberger, Yeates & Hobbs, submitted). Specific mentalization-based psychotherapies have been applied to a range of clinical groups (Bateman & Fonagy, 2012) and Yeates (2014) has advocated for the use of such approaches with survivors of ABI to support survivor mental health and their relationships with others (including clinicians). If these interventions become more prominent within neuro-rehabilitation, the differing clinical significance of deficits in 1st order versus 2nd order mentalising representations, and/or epistemic, affective and intentionality representations will need to be discerned. While the current study only found impairments in 1st order representation and did not find significant differences between patients and controls on 2nd order or other mentalising indices, these findings need to be replicated with other brain injury and control groups and with additional measures.

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REFERENCES

- Adams, A., Schweitzer, D., Molenbergh, P. & Henry, J. (2019). A meta-analytic review of social cognitive function following stroke. *Neuroscience & Biobehavioral Reviews*, 102, 400-416.
- Baguley, I., Cooper, J., & Felmingham, K. (2006). Aggressive behavior following traumatic brain injury. How common is common? *Journal of Head Trauma Rehabilitation*, 19, 314-328.
- Baron-Cohen, S., Leslie, A.M., & Frith, U. (1986). Mechanical, behavioural and intentional understanding of picture stories in autistic children. *British Journal of Developmental Psychology*, 4, 113-125.
- Bateman AW. & Fonagy P. *The Handbook of Mentalization-Based Therapy in Mental Health Practice*. 2012; New York: American Psychiatric Publishing.
- Benedictus, M., Spikman, J., & van der Naalt, J. (2010). Cognitive and behavioural impairment in traumatic brain injury related to outcome and return to work. *Archives of Physical and Medical Rehabilitation*, 91, 1436 - 1441
- Bivona, U., Riccio, A., Ciurli, P., Carlesimo, G., Delle Donne, V., Pizzonia, E., Caltagirone, C., ... Costa, A. (2014). Low self-awareness of individuals with severe traumatic brain injury can lead to reduced ability to take another person's perspective. *Head Trauma Rehabilitation*, 29, 157-171.
- Blonder, L. Z., Pettigrew, L. C., & Kryscio, R. J. (2012). Emotion recognition and marital satisfaction in stroke. *Journal of Clinical & Experimental Neuropsychology*, 34, 634-642.
- Channon, S., & Crawford, S. (2000). The effects of anterior lesions on performance on a story comprehension test : left anterior impairment on a theory of mind-type task. *Neuropsychologia*, 38, 1006- 1017.
- Frith, C., Frith, U. (2006). Neural basis of mentalizing. *Neuron*, 50, 531-534.
- Geraci, A., Surian, L., Ferraro, M., Cantagallo, A. (2010). Theory of Mind in patients with ventromedial or dorsolateral prefrontal lesions following traumatic brain injury. *Brain Injury*, 24, 978-987.
- Gregory, C., Lough, S., Stone, V., Erzinclioglu, S., Martin, L., Baron-Cohen, S., & Hodges, J. (2002). Theory of mind in patients with frontal variant frontotemporal dementia and Alzheimer's disease: Theoretical and practical implication. *Brain*, 125, 752-764.
- Happé, F., Brownell, H., & Winner, E. (1999). Acquired 'theory of mind' impairments following stroke. *Cognition*, 70, 211-240.
- Happé, F., Malhi, G., & Checkley, S. (2001). Acquired mind-blindness following frontal lobe surgery? A single case study of impaired 'theory of mind' in a patient treated with stereotactic anterior capsulotomy. *Neuropsychologia*, 39, 83-90.
- Kelly, G., Brown, S., Todd, J., & Kremer, P. (2008). Challenging behaviour profiles of people with acquired brain injury living in community settings. *Brain Injury*, 22, 457-470.
- Knox, L., Douglas, J. (2009) Long-term ability to interpret facial expression after traumatic brain injury and its relation to social integration. *Brain and Cognition*, 69, 442-449.
- Lee, T., Ip, A., Wang, K., Xi, C., Hu, P., Mak, H., Han, S., Chan, C. (2010). Faux pas deficits in people with medial frontal lesions as related to impaired understanding of a speaker's mental state. *Neuropsychologia*, 48, 1670-1676.
- Leekam, S., & Perner, J. (1991). Does the autistic child have a metarepresentational deficit? *Cognition*, 40, 203-218
- Leopold, A., Krueger, F., dal Monte, O., Pardini, M., Pulaski, S., Solomon, J., Grafman, J. (2012) Damage to the left ventromedial prefrontal cortex impacts affective theory of mind. *SCAN*, 7, 871-880
- Martín-Rodríguez, J., León-Carrión, J. (2010). Theory of mind deficits in patients with acquired brain injury: A quantitative review. *Neuropsychologia*, 48, 1181-1191
- McLellan, T. & Mckinlay, A. (2013). Sensitivity to emotion, empathy and theory of mind: Adult performance following childhood TBI. *Brain Injury*, 27, 1032-1037.
- Milders, M., Ietswaart, M., Crawford, J., Currie, D. (2006). Impairments in 'theory of mind' shortly

- after traumatic brain injury and at one-year follow-up. *Neuropsychology*, *20*, 400–408.
- Milders, M. (2018): Relationship between social cognition and social behaviour following traumatic brain injury. *Brain Injury*, DOI: 10.1080/02699052.2018.1531301
- Muller, F., Simion, A., Reviriego, E., Galera, C., Mazaux, J., Barat, M., & Joseph, P. (2010). Exploring theory of mind after severe traumatic brain injury. *Cortex*, *46*, 1088-1099
- Neumann, D., Malec, J.F. & Hammond, F/M. (2015) The association of negative attributions with irritation and anger after brain injury. *Rehabilitation Psychology*, *60*, 155
- Olson, I.R., Plotzker, A. & Ezzyat, Y. (2007). The Enigmatic temporal pole: a review of findings on social and emotional processing. *Brain*, *130*, 1718-1731.
- Samson, D., Apperly, I. A., Chiavarino, C., & Humphreys, G. W. (2004). Left temporoparietal junction is necessary for representing someone else's belief. *Nature Neuroscience*, *7*, 499–500.
- Schönberger, M., Yeates, G.N. & Hobbs, P. (submitted) Associations between therapeutic working alliance and social cognition in neuro-rehabilitation..
- Spikman J, Milders M, Visser-Keizer A, Westerhof-Evers H, Herben-Dekker M, van der Naalt J. (2013). Deficits in facial emotion recognition indicate behavioral changes and impaired self-awareness after moderate to severe traumatic brain injury. *PLoS One*, *8*, 1-7.
- Stone, V., Baron-Cohen, S., Calder, A., Keane, J., & Young, A. (2003). Acquired theory of mind impairments in individuals with bilateral amygdala lesions. *Neuropsychologia*, *41*, 209-220.
- Stone, V., Baron-Cohen, S., & Knight, R. (1998). Frontal lobe contributions to theory of mind. *Journal of Cognitive Neuroscience*, *10*, 640-656.
- Struchen, M., Pappadis, M., Sander, A., Burros, C., Myszka, K. (2011). Examining the contribution of social communication ability and affect/behavioral functioning to social integration outcomes for adults with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *26*, 30-42.
- Yeates, G.N. (2014). Social cognition interventions in neuro-rehabilitation: An overview. *Advances in Clinical Neuroscience & Rehabilitation*, *14*(2), 12-13.
- Yeates, G., Rowberry, M., Dunne, S., Goshawk, M., Mahadevan, M., Tyerman, R., . . . Tyerman, A. (2016). Social cognition and executive functioning predictors of supervisors' appraisal of interpersonal behaviour in the workplace following acquired brain injury. *NeuroRehabilitation*, *38*, 299-310. doi:10.3233/NRE-16132
- Zupan, B., Neumann, D., Babbage, D. & Willer, B. (2014). Using Social Stories to Assess Emotional Inferencing of People with Traumatic Brain Injury (TBI). *Brain Injury*, *28*, 594-594

ASSOCIATIONS BETWEEN THERAPEUTIC WORKING ALLIANCE AND SOCIAL COGNITION IN NEURO-REHABILITATION

ASOCIACIONES ENTRE LA ALIANZA TERAPÉUTICA DE TRABAJO Y LA COGNICIÓN SOCIAL EN LA NEURO-REHABILITACIÓN

MICHAEL SCHÖNBERGER*¹, GILES YEATES² & PIRAN HOBBS³

* Correspondencia:

Michael Schönberger

michael_schoenberger@web.de

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The aim of this study was to investigate the impact of brain injury survivors' social cognition abilities on their working alliance with their therapist. Participants in this study were individuals who were enrolled in a vocational rehabilitation programme for acquired brain injury. Seventy-two individuals with complicated mild to severe acquired brain injury (49% TBI, 38% stroke, 14% other injury; mean age 44.9 years; 75% male) entered in the study between 1.5 and 31 years after their injury (Md=5 years). The therapeutic alliance was rated retrospectively at the time of study by the participants' primary therapists on the Working Alliance Inventory (WAI). Social cognition measures (Reading the Mind in the Eyes Test, Recognition of Faux Pas Test, The Awareness of Social Inference Test, TASIT; Social Situations Task, Bangor Gambling Task) were administered as well as a standard neuropsychological test battery and the Hospital Anxiety and Depression Scale. Multilevel analyses revealed that both the TASIT and the Social Situations Task, but neither the standard neuropsychological tests nor the HADS were significantly related to WAI ratings. These findings indicate the impact that difficulties with emotions recognition and social rule violations can have on the formation of a therapeutic alliance.

Keywords: Therapeutic working alliance; social cognition; emotion recognition; brain injury; rehabilitation

El objetivo de este estudio fue investigar el impacto de las habilidades de cognición social de los supervivientes de lesiones cerebrales en su alianza de trabajo con su terapeuta. Los participantes en este estudio fueron individuos que se inscribieron en un programa de rehabilitación profesional para la lesión cerebral adquirida. Setenta y dos individuos con lesión cerebral adquirida complicada de leve a grave (49% TBI, 38% accidente cerebrovascular, 14% otra lesión; media edad 44,9 años; 75% hombres) entraron en el estudio entre 1,5 y 31 años después de su lesión (MD=5 años). La alianza terapéutica fue calificada retrospectivamente por los terapeutas principales de los participantes con el Working Alliance Inventory (WAI). Se administraron medidas de cognición social (Reading the Mind in the Eyes Test, Recognition of Faux Pas Test, The Awareness of Social Inference Test, TASIT; Social Situations Task, Bangor Gambling Task), así como una batería de pruebas neuropsicológicas estándar y la escala de ansiedad y depresión hospitalaria (Hospital Anxiety and Depression Scale). Los análisis multinivel revelaron que tanto TASIT como Social Situations Task, estaban significativamente relacionados con las calificaciones de WAI. Estos resultados indican el impacto que las dificultades en el reconocimiento de las emociones y las violaciones de las reglas sociales pueden tener en la formación de una alianza terapéutica.

Palabras claves: alianza terapéutica de trabajo, cognición social, reconocimiento de emociones, lesión cerebral, rehabilitación

¹ Affiliation during the study. Department of Rehabilitation Psychology, University of Freiburg, Germany

² Centre for Movement, Occupational & Rehabilitation Sciences (MORes), Oxford Brookes University, UK

³ Community Head Injury Service, Buckinghamshire Healthcare NHS Trust, Aylesbury, UK.

A strong working alliance (also called therapeutic alliance) is commonly regarded an important aspect of successful therapeutic process in various clinical settings (Henry, Strupp, Horvath, & Greenberg, 1994). Its impact on therapy outcome has been confirmed in a large number of studies as well as in several meta-analyses (Fluckiger, Del Re, Wampold, Symonds, & Horvath, 2012; Horvath & Symonds, 1991; Martin, Garske, & Davis, 2000). Following the definition of Bordin (1979), a strong working alliance is characterised by a strong emotional bond between client and therapist, agreement between client and therapist regarding the goals to be achieved during therapy, as well as effective work on certain tasks in order to achieve these goals.

In the context of brain injury rehabilitation, several studies have consistently demonstrated the importance of a good working alliance for a successful outcome (for a review, see Stagg, Douglas, & Iacono, 2017). Good working alliances with between individuals with acquired brain injury and rehabilitation professionals have been reported to be related to better participation outcomes in terms of work/school (Klonoff, Lamb, & Henderson, 2001; Prigatano et al., 1994; Schönberger, Humle, Zeeman, & Teasdale, 2006b; Sherer et al., 2007) and driving (Klonoff et al., 2010) outcomes as well as reduced emotional distress (Evans et al., 2008; Schönberger, Humle, & Teasdale, 2006b). The working alliance also affects other variables that are of importance for a successful rehabilitation (Schönberger, Humle, Zeeman, & Teasdale, 2006a), namely brain injury survivors' awareness as well as their engagement in the rehabilitation process (Schönberger, Humle, & Teasdale, 2006a; Schönberger, Humle, Zeeman, et al., 2006b).

Outside of the rehabilitation setting, it is acknowledged that social relationships of all kinds are widely strained by the enduring impact of acquired brain injury. These include romantic relationships (Gervasio & Kreutzer, 1997; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011), relationships with parents (Anderson et al., 2009), siblings and child relatives of adult brain injury survivors (Daisley & Webster, 2009; Niemela et al., 2014). Furthermore, difficulties in friendships (Salas, Casassus, Rowlands, Pimm, & Flanagan, 2016) and wider community relationships are evident, with social isolation for survivors being an increasingly likely outcome as time progresses post-injury (Elsass & Kinsella, 1987). Loss of work roles, demotion and unemployment post-injury have been linked to difficulties in relationships with work colleagues (Yeates et al., 2016). Cognitive, behavioural, and mood

changes post-injury have been shown to have a negative influence on family relationships (Ponsford & Schönberger, 2010; Schönberger, Ponsford, Olver, & Ponsford, 2010).

If social relationship breakdown is so widespread and pervasive post-injury, then relationships with clinicians in the rehabilitation settings are unlikely to be immune to the same influences and processes. In particular, therapeutic working alliances with clinicians in those brain injury services who support survivors over long periods of time are likely to be most compromised by the same injury-related challenges that impact on the long-term personal relationships described above. Lewis (1999) has described challenging relationship dynamics between survivors and clinicians, including powerful emotional responses from clinicians themselves. Yeates and colleagues (2008) presented two case studies of psychotherapy with brain injury survivors with executive difficulties, to show how the management of the therapeutic relationship was central to clinical progress.

Few researchers have investigated direct influences of survivor variables on therapeutic working alliance with clinicians in neuro-rehabilitation. In a qualitative study by Judd & Wilson (2005), therapists reported that the formation of a working alliance in brain injury rehabilitation is often complicated by survivors' cognitive deficits, such as slowed information processing speed or forgetting therapeutic commitments. One quantitative study could only partly confirm these findings. In their longitudinal study, measures of attention, memory as well as executive functioning were related to the working alliance between clients and therapists (Schönberger, Humle, & Teasdale, 2007). However, the associations were weak. The authors suggest that the latter was due to the fact that the therapists were trained in dealing with their clients' cognitive profile. Moreover, the study was limited to measures of participants' attentional, memory and executive functioning. Rowlands, Coetzer and Turnbull (2020) found survivor working and episodic memory to be predictors of engagement in a group psychoeducation programme. However no other cognitive functioning variable predicted therapeutic working alliance or engagement. Predictors of working alliance identified in this study were survivor years of education and levels of depressive symptomatology at the time of data collection. Zelencich and colleagues (2020) found time post-injury (but no other survivor demographic or cognitive variable) to be predictive of engagement in a cognitive-behavioural therapy intervention within neuro-rehabilitation.

Recent research has indeed highlighted the particular influence of survivor social cognition difficulties on social relationships of different kinds, such as romantic relationships (Blonder, Pettigrew, & Kryscio, 2012), community integration (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011) and relationships with work colleagues (G. N. Yeates et al., 2016). Social cognition refers to abilities directly related to socially-interactive processes between people, and includes a range of diverse functions mediated by distributed neuro-anatomical networks (Frith & Wolpert, 2004). Functions of this kind that are shown to be commonly impaired in survivors of acquired brain injury include mentalising/theory of mind (Channon & Crawford, 2000), sarcasm detection (Channon, Pellijeff, & Rule, 2005) and other forms of social inference (McDonald, Flanagan, Rollins, & Kinch, 2003), emotion recognition (Hornak et al., 2003), social judgment, social decision-making and problem-solving (Blair & Cipolotti, 2000), and interoceptive-based decision-making (Bechara, Damasio, Damasio, & Anderson, 1994). These deficits have been demonstrated in the major subgroups of acquired brain injury, such as traumatic brain injury, stroke, hypoxia, infection and post-tumour resection (for a review, see G.N. Yeates, 2013).

Given the impact of social cognition impairments on social relationships, it could be argued that survivor abilities in social cognition are more likely to be strongly associated with clinician ratings of therapeutic working alliance, than other domains of cognition explored in the few aforementioned studies of Therapeutic Working Alliance in neuro-rehabilitation (none of which have measured survivor social cognition to our knowledge). If this was demonstrated to be the case, such findings would highlight survivor social cognition difficulties as not only clinically-significant foci for rehabilitation, but also a central consideration to the optimisation of the rehabilitation process itself. That is, the management of social cognition difficulties and improved communication/social interactions between clinicians and survivors may improve their therapeutic working alliance. This in turn may ultimately improve rehabilitation outcome.

STUDY AIMS AND HYPOTHESES

The aim of the current study was to investigate relationships between the therapeutic working alliance in brain injury rehabilitation and key social cognition abilities (emotion recognition, mentalising, social inference, social judgment-making and emotion-based decision-making).

Based on the existing literature on the impact of social cognition on social relationships as well as the authors' clinical experience, we hypothesized low levels of social cognition skills to have a negative impact on the working alliances between participants and their primary therapist. We also examined whether the strength of the working alliance was specifically related to social cognition skills, or whether it was also associated with other neuropsychological functions. Regarding this latter study aim, based on previous results discussed above, only weak or no associations were expected between working alliance and other neuropsychological functions.

METHODS

Design and participants

This is one of a series of studies investigating survivor social cognition as predictors of differing interpersonal relationships (the *Social Cognition, So What?* research programme, also see Yeates et al., 2016). Participants in this study were working-age individuals (16 years +) who were enrolled in three UK community and vocational rehabilitation programmes for acquired brain injury (traumatic brain injury, ischaemic and haemorrhagic stroke, infections, hypoxia, post-tumour resection). These services were the Community Head Injury Service, Aylesbury, and Momentum Skills in Birmingham and Newcastle. To be eligible for these services, all participants were not presenting with gross behavioural difficulties (e.g., aggression, extreme socially- and sexually-disinhibited behaviour), although many did exhibit subtle interpersonal difficulties, all were independent in activities of daily living, and any communication difficulties were amenable to compensatory support to permit the participation within the rehabilitation programmes. For the purpose of this study, an additional exclusion criterion was a reading difficulty that would impede the comprehension of the written content in the neuropsychological tests and questionnaires.

Participants' emotion recognition skills as well as their understanding of social situations were assessed at the beginning of their rehabilitation. Their working alliance with their primary therapist was rated retrospectively by the respective therapist at the time of conduct of this study. By profession, the therapists were clinical neuropsychologists, occupational therapists/occupational therapist technicians, vocational consultants, psychology assistants or nurses, all of whom had worked with participants for a minimum of six

months, up to 5 years, often alongside other staff members within an interdisciplinary service structure. Raters were aware that the study was investigating the influence of survivor neuropsychological functioning on the therapeutic working relationship, but not aware of which domains of cognition were of particular interest to the investigators.

Seventy-two individuals with acquired brain injury entered the study, the majority of them men. Participants' demographic and injury-related characteristics are displayed in Table 1. Their age followed a symmetric, unimodal distribution with a wide range (19-68 years). Individuals had sustained their injury between one and a half and 31 years earlier, with half the sample being within the first five years post-injury and 75% within eight years post-injury. Most of the participants had had either a traumatic brain injury (TBI) or a stroke, while the remaining injuries included hypoxia, infection, brain tumour as well as other injuries. Information regarding injury severity was not consistently available for all participants (34 records of duration of post-traumatic amnesia (PTA), 24 records of GCS). The existing data is in agreement with the clinical picture, namely a wide range of injury severity from complicated mild (persisting difficulties over one year, with significant co-morbid executive dysfunction) to very severe. Eligibility for the three participating clinical services was based on a complicated mild to severe brain injury where this could be assessed, although specific GCS and PTA scores were not available for all participants, nor applicable to non-TBI forms of acquired brain injury. Twenty-four percent of the sample self-reported in a demographics questionnaire that they had experienced depression, anxiety or another form of mental health problem prior to their injury. This study received full ethical approval from the local NHS ethics committee (NRES Oxfordshire REC B) and research and governance body (Buckinghamshire Healthcare NHS Trust R&D committee).

Measures

Primary Outcome Measure: Working Alliance Inventory (WAI)

The WAI (Horvath & Greenberg, 1989) has been developed for and has been frequently used in the context of psychotherapy research. It is based on Bordin's (1979) theory of working alliance and comprises three subscales: The Bond subscale assesses the strength of emotional bond between client and therapist. The Goal scale measures the extent of clients' and therapists' agreement regarding the goals to be achieved during therapy. The Task scale assesses

how effectively client and therapist work on certain tasks in order to achieve their goals. Each subscale comprises 12 items, rated on a seven-point Likert scale ranging from one ("Never") to seven ("Always"). Item scores are added up in order to compute subscale scores, as well as a Total score. In the current study, the WAI therapist version was administered to the participants' primary therapist. In the context of brain injury rehabilitation, the WAI scales have been shown to have good internal consistency (for WAI Total Therapist scale: Cronbach's $\alpha=.86$, retest reliability $r=.75$; (Schönberger, Humle, & Teasdale, 2006a).

Survivor Mood: Survivor emotional functioning was assessed using a self-report questionnaires of anxiety and depression (Hospital Anxiety & Depression Scale, HADS; Zigmond & Snaith, 1983) that has been validated for the brain injury population (Schönberger & Ponsford, 2010; Whelan-Goodinson, Ponsford, & Schönberger, 2009).

Tests of social cognition: Measures included tests of mentalising/theory of mind, the ability to infer the intentions and perspectives of others. These measures were based on two types of stimuli, static visual stimuli and story vignettes. In the Reading the Mind in the Eyes Test (Baron-Cohen et al., 2001), participants are required to identify the correct mental state (e.g., despondent) from a selection of four to match to a photograph of a human face restricted to the eye area. Scores range from 0-36.

The Recognition of Faux Pas Test (Baron-Cohen et al., 1999) involves twenty written vignettes of social interactions, ten of which involve the occurrence of an unintentional faux pas that potentially offends a character. Each vignette has four questions that test mentalising abilities, with answers either being scored as incorrect (=0) or correct (=1; total score range 0-40). In addition, one control question assesses working memory and comprehension (score range 0-20). In our study, the standard total score out of 40 for the 10 faux pas stories was used.

Mentalising has been identified as an essential component of wider forms of social inference, such as the detection of differing forms of sarcasm, sincerity and deceit. These abilities were tested using the video social scenario stimuli in parts 2 and 3 from The Awareness of Social Inference Test (TASIT; McDonald et al., 2003). In response to yes/no questions, correct scores range from 0-20 for detection of expressions of Sincerity, Deceit and Sarcasm.

Additional social cognition abilities tested included video-based assessment of emotion recognition,

Table 1: Participants' demographic and injury-related characteristics

		N (%)
Sex	Male	54 (75)
	Female	18 (25)
Injury type	Traumatic brain injury	35 (49)
	Stroke	27 (38)
	Other	10 (14)
Pre-injury mental health issues	None	48 (76)
	Anxiety/depression	11 (17)
	Other	4 (6)
		Mean (SD), Median, Range
Age (years)		44.9 (11.0), 45, 19-68
Time since injury (years)		6.9 (6.5), 5, 1.5-31.3

operationalising the six basic emotions (happiness, surprise, sadness, anger, anxiety, disgust/revulsion, plus neutral expressions) and also yielding total scores for positive versus negative emotion recognition (Emotion Evaluation Test, Part 1 of the TASIT; McDonald et al., 2003). Emotion-matching scores range from 0-4 for each emotion (happiness, surprise, neutral, anger, anxiety, sadness, disgust).

In addition we used a vignette-based task of social judgement-making, assessing participants' detection of social norms violations and also discriminating the degree of violation, such as distinguishing an instance of taking 12 items into a 10 items or less checkout queue versus someone touching a stranger's baby (Social Situations Task; Dewey, 1991).

The final social cognition test was a gamble task paradigm of emotion-based decision-making (Bangor Gambling Task; Bowman & Turnbull, 2004). The score was based on the number of good choices minus number of bad choices, ranging from -100 to +100. This was based on the assumption in the gambling task literature that disadvantageous performance on these tasks is commensurate with difficulties in making decisions in ambiguous social situations that require a weighing up of short-term versus long-term gains for self and others (Damasio, 1994).

In addition, other domains of cognition were measured using the following neuropsychological tests: As

tests of executive functioning, the Delis-Kaplan Executive Function Syndrome Test (D-KEFS; Delis, Kaplan, & Kramer, 1991)- Letter Fluency Scaled Score, the Hayling Sentence Completing Test and the Brixton Spatial Anticipation Test (Total Sten Scores; Burgess & Shallice, 1997), as well as the Zoo Map and Six Elements subtests of the Behavioural Assessment of the Dysexecutive Syndrome (BADS, raw scores; Wilson, Emslie, Evans, Alderman, & Burgess, 1996) were employed. Participants' visual selective attention, attentional switching and sustained attention was assessed with the following respective subtests of the Test of Everyday Attention (TEA; I. Robertson, Nimmo-Smith, Ward, & Ridgeway, 1994): Map Search II, Visual Elevator Timing and Lottery. Both working memory and episodic recall were measured with the Wechsler Memory Scale III (WMS; Wechsler, 1997) Working Memory Index and Modified Delayed Recall Index.

Statistical analysis

Descriptive statistics were computed for all variables of interest. For all further analyses, participants' type of brain injury was recoded into three categories (TBI vs. stroke vs. other injury types). Similarly, the occurrence of pre-injury mental health issues was recoded into three categories (none vs. anxiety or depression vs. other mental health

issues). Bivariate relationships between demographic, injury-related variables as well as survivors' mood on the one hand and WAI scales on the other were examined with analyses of variance (ANOVA) as well as Pearson's correlations. In order to examine the relationship between working alliance and neuropsychological tests, multilevel regression analyses were performed, with clients nested in therapists. This procedure takes into account that in this study, therapists had more than one of the participants as their client, and therapists differ from each other with respect to the way they form working alliances. In other words, individual clients' data could not be treated as independent information, and this is taken into account by the multilevel regression analyses employed. For the prediction of each WAI scale (Task, Bond, Goal, Total) from one of the neuropsychological tests, a series of multilevel regression analysis was computed, controlling for demographic and injury-related variables significantly related to the WAI scales. The level of significance was set to .05. All analyses were performed with IBM® SPSS® Statistics Version 22 (IBM_Corp., 2013).

RESULTS

Measurement descriptives

Descriptive information for the WAI scales as well as all neuropsychological tests are displayed in Table 2. Scores on all WAI scales were similar, ranging from 5.1 (WAI Goal) to 5.3 (WAI Task). Most working alliance ratings were either neutral or positive, with a lowest score of 2.4 on the WAI Goal scale (on a scale ranging from one to seven). The survivor means and standard deviations on the neuropsychological tests indicate a performance significantly below the published means for healthy controls on the Recognition of Faux Pas Test, Reading the Mind in the Eyes Test, disgust recognition from TASIT Part 1, Bangor Gambling Task, Key Search and Zoo Map subtests from the BADS, Hayling Sentence Completion Test, Brixton Spatial Anticipation Test, and both Map Search and Visual Elevator subtests from the TEA. Individual survivor scores varied on either side of clinical cut-offs for every measure. As such, the sample can be collectively described as demonstrating difficulties in mentalising, recognition of disgust, emotion-based decision-making, various aspects of executive functioning, visual selective attention and attentional switching. In contrast the sample as a whole does not demonstrate difficulties in the recognition of all the other primary emotions,

social inference, initiation of novel verbal responses, sustained attention, working memory and episodic recall.

Relationship between participants' demographic and injury related characteristics, mood and working alliance

Of the demographic and injury related variables, women had significantly higher WAI Task, Goal and Total scores than men (ANOVAs; all $p < .05$). Participants who had had a stroke had higher scores (between 5.3 on WAI Goal and 5.5 on WAI Task) on all WAI scales than individuals who had sustained a TBI (score of 5.1 on WAI Goal scale and 5.2 on all other WAI scales) and individuals who had had another kind of injury (scores between 4.3 on the WAI Goal scale and 4.6 on the WAI Task scale; ANOVAs, all $p < .05$). Participants who reported anxiety or depression prior to their injury had significant lower scores on the WAI Bond scale (average score 4.6) as compared to individuals who reported another form of pre-injury mental health issue (average score 5.5) or no prior mental illness (average score 5.3) (ANOVA; $p < .05$). Survivors' mood at the time of rehabilitation was not significantly related to WAI ratings (Pearson's correlations; all $p > .05$).

Relationship between working alliance and neuropsychological test results

A series of multilevel regression analysis was computed predicting each WAI scale (Task, Bond, Goal, Total) from one of the neuropsychological tests, controlling for participants' gender, type of injury as well as the occurrence of pre-injury mental health issues. The TASIT Part 1 (emotion evaluation) Total score was significantly related the WAI Task, Goal and Total scales. The TASIT Part 1 Total Negative Emotions score was significantly related to the WAI Task and Total scales and close-to-significantly ($p < .1$) related to the WAI Goal scale. The TASIT Part 3 Sarcasm score was close-to-significantly related to the WAI Task, Goal and Total scales. The Social Situations Task Appropriateness score was significantly related to the WAI Task and Goal scales (See Table 3). None of the tests of executive functions, attention or working memory was significantly related to the WAI scales.

DISCUSSION

This study has produced empirical evidence to support the hypothesised relationship between some, but not all aspects of survivor social cognition abilities and clinicians' ratings of therapeutic working alliance. Survivor difficulties

Table 2: Descriptive statistics for questionnaire and neuropsychological tests

Scale/test	Sample Mean (SD)	Range	Norm Mean (SD)
WAI Task	5.3 (.9)	3.0-7.0	
WAI Bond	5.2 (.8)	2.8-6.6	
WAI Goal	5.1 (1.0)	2.4-7.0	
WAI Total	5.2 (.8)	3.0-6.7	
Faux Pas Questions (/40)	27.2 (6.8)	8-39	35.5 (3.0)
Faux Pas Control (/10)	9.8 (.6)	7-10	
Mind in the Eyes (/40)	23.7 (4.6)	12-33	26.2 (3.6)
TASIT Part 1 Total Positive Emotions	9.0 (2.1)	1-16	
TASIT Part 1 Total Negative Emotions	12.3 (2.8)	4-19	
TASIT Part 1 Total	21.3 (4.1)	9-35	24.9 (2.11)
TASIT Part 2 Sincere	15.4 (4.0)	4-20	16.5 (3.3)
TASIT Part 2 Sarcasm (simple & paradoxical)	34 (36)	13-40	
TASIT Part 2 Total	49.5 (6.6)	29-58	54.1 (4.3)
TASIT Part 3 Lie	25.9 (3.9)	13-32	27.8 (2.9)
TASIT Part 3 Sarcasm (Enriched)	23.8 (4.7)	12-37	27.9 (3.2)
TASIT Part 3 Total	50.0 (7.0)	33-66	55.6 (3.0)
Bangor Gamble Task - No. Good Choices - Bad Choices	-4.2 (27.1)	-78-56	13.2 (22.4)
Social Situations Task Normative Score (/12)	9.8 (1.5)	6-12	9.3 (1.3)
Social Situations Task Violation Score (/12)	9.5 (2.0)	5-12	9.9 (1.4)
Social Situations Task Appropriateness Score (/36)	16.6 (5.8)	5-31	19.6 (6.4)
Letter Fluency Scaled Score (D-KEFS)	8.8 (3.7)	1-18	
BADS Zoo Map	10.6 (5.0)	-6-16	
BADS Six Elements	4.7 (1.5)	1-6	
Hayling Total Sten Score	5.0 (1.4)	1-7	6.1 (1.6)
Brixton Total Sten Score	5.7 (2.2)	1-10	6.1 (1.6)
TEA Map Search II	5.5 (4.0)	0-16	
TEA Visual Elevator Timing	6.7 (5.0)	0-19	10.0 (3.0)
TEA Lottery	8.3 (3.8)	0-13	
WMS III Working Memory Index	98.2 (15.2)	63-127	100 (15)
WMS III Modified Delayed Recall Index	10.4 (3.2)	3.5-17	

¹ WAI= Working Alliance Inventory, therapist version; Faux Pas = Recognition of Faux Pas Test; Mind in the Eyes = Reading the Mind in the Eyes Test; TASIT = The Awareness of Social Inference Test; D-KEFS = Delis-Kaplan Executive Function System; BADS = Behavioural Assessment of Dysexecutive Syndrome; Hayling = Hayling Sentence Completion Test; Brixton - Brixton Spatial Anticipation Test; TEA = Test of Everyday Attention; WMS III = Wechsler Memory Scale, Third Edition.

Table 3: Significant relationships between neuropsychological test results and therapists' retrospective working alliance ratings

NP test	WAI task	WAI bond	WAI goal	WAI total
TASIT Part 1 Total negative emotions	.06*	n.s.	n.s.	n.s.
TASIT Part 1 Total	.05**	n.s.	.07*	.04*
TASIT Part 2 Sarcasm	.03*	n.s.	.05**	.03*
Social situation appropriateness score	.03*	n.s.	.04*	n.s.

Each table cell represents a multilevel analysis (survivors nested in therapists) predicting a WAI scale from one of the neuropsychological tests, controlling for gender, injury type and the presence of mental health issues prior to the brain injury

¹WAI= Working Alliance Inventory, therapist version

* = $p < .05$; **= $p < .01$

in emotion recognition and the discrimination of differing degrees of social rule violations are related to clinicians' perceptions of poorer therapeutic relationships with those survivors. Survivor social inference abilities, operationalised as sarcasm detection, was also associated with working alliance ratings. Of note, and in agreement with our hypothesis, none of the tests of executive functioning was related to the strength of the working alliance.

This data can be used to add to previous findings indicating the varied negative social impact of survivor social cognition difficulties (Blonder et al., 2012; Struchen et al., 2011; Yeates et al., 2016), extending the list of outcomes to include marital relationships, community integration and now therapeutic working alliance with clinicians. This of course supports the face value assumption that difficulties in social cognition will exert a particular influence on social relationships as opposed to personal and functional outcomes.

However, there is something particularly significant about survivor relationships with clinicians being adversely affected alongside romantic partners, relatives, friends and work colleagues. It is the brain injury clinician that the survivor (or their significant other) turns to in order to seek assistance in managing the impact of breakdown in the other forms of social relationship. Most approaches to rehabilitation assume a collaborative relationship between survivors and clinicians, and previous research has shown that a good therapeutic working alliance is related to both rehabilitation outcome (Klonoff et al., 2010; Schönberger, Humle, & Teasdale, 2006b; Schönberger, Humle, Zeeman, et al., 2006b; Sherer et al., 2007) and survivors' awareness of their difficulties and engagement in rehabilitation (Schönberger, Humle, & Teasdale, 2006a; Schönberger,

Humle, Zeeman, et al., 2006b), in turn also related to rehabilitation outcome (K. Robertson & Schmitter-Edgecombe, 2015; Schönberger, Humle, Zeeman, et al., 2006a, 2006b). So if the therapeutic relationship with clinicians is in itself compromised and challenged by social cognition difficulties, this relationship may become one more unfortunate negative interpersonal outcome and thus leave the survivor with no support at all to manage the other social crises.

Difficulties in the relationship between survivors and clinicians have been explored by previous authors. Lewis (Lewis, 1999) cautions against the wildly oscillating and complicated relationship patterns between traumatic brain injury survivors and therapists, often marked by intense affect. Lewis uses the psychoanalytical conception of transference and counter-transference, the enactment of wider relationship patterns, thoughts and feelings in the relationship between client and therapist, including the therapists' own responses to clients. Lewis outlines how in response to either a survivor's idealisation or denigration of the therapist, the clinician can experience pride or uneasiness in the case of the former, or anger and submission in the case of the latter.. These are complex feelings and interactional patterns, yet are rarely explored within services that operate under the assumption of an unproblematic collaborative relationship with survivors.

The difficulties in emotion recognition and social inference abilities, as well as the degree of social rule violation detection highlighted here as related to clinicians' ratings of working alliance could be conceptualised as leading survivors to misinterpret the expressions and communications of the therapist (e.g., positive or neutral expression being misperceived as negative, critical and aversive; misinterpreting

sincere communications to be sarcastic or deceitful), or social boundaries and respectful behaviour transgressed without realising the impact of such on the therapist (and then struggling to register the clinician's emotional reaction to these transgressions). The presence of such difficulties may result in repairs of ruptures in the working alliance being unlikely, especially if the clinician is not supported to think about and manage such issues. Klonoff (2015) has highlighted how clinicians need to be supported in supervision to manage negative feelings such as disappointment in response to the enduring nature of survivor difficulties, and then minimise the 'toxicity' of such responses to the therapeutic relationship. In a review of social cognition rehabilitation interventions, Yeates (2014) has suggested that individual psychodynamic interventions such as mentalization-based therapy (Bateman & Fonagy, 2012) offer potential in supporting the impact of survivor social cognition difficulties on their significant others, through active use of the relationship with the therapist, including sharing the therapist's own emotional responses to the survivor's interpersonal challenges. This and other psychodynamic therapies would simultaneously support clinicians' own wellbeing through the vocabulary and focus it provides on interpersonal events and social cognition processes in the therapy room. Yeates (2014) cautions that at the current level of social cognition rehabilitation development, social skills, emotion recognition and mentalisation training/strategies lack the efficacy and responsiveness to have an effective impact on non-scripted, complex, evolving social interactions. Therapeutic interactions with clinicians would be of this kind.

Of note, in this study, low levels of social cognition were not associated with therapists' ratings of the emotional bond with their clients. The WAI Therapist Bond scale assesses the therapists' respect for, appreciation and acceptance of the patient as well as the therapist's empathy, congruence and commitment and a sense of mutual trust. Negative feelings that might arise from social interaction difficulties such as frustration or anger are not covered by the WAI. Only one question refers to the therapist feeling uncomfortable with the client. It could therefore be argued that the negative emotional consequences that social cognition difficulties can have for one or all parts of a social interaction are not properly covered by the WAI Bond scale.

Beyond the dyad of the survivor and therapist, Klonoff (2015) has also highlighted how complex dynamics within

a team of clinicians can be a key dimension of the everyday work of neuro-rehabilitation. It would be important to conceptualise and manage the impact of survivor social cognition difficulties on multiple clinicians working with them and any escalating responses within the entire team that may not be conducive to the wellbeing of either survivors or clinicians. Several authors have described how neuropsychological consequences of acquired brain injury can be addressed within the framework of a therapeutic milieu approach to neuro-rehabilitation (Caetano, Christensen, Uzzell, & Christensen, 2000; Christensen, Caetano, Stuss, Winour, & Robertson, 1999; Daniels-Zide, Ben-Yishay, Uzzell, & Christensen, 2000; Prigatano et al., 1994). Cognitive rehabilitation is here extended beyond the individual client-therapist dyad, and even beyond group settings, to a holistic approach within which all staff interactions with the client can be used to support survivors in becoming aware of and dealing with their social cognition difficulties.

A number of study limitations are evident. This study has a retrospective design, which means that the therapists' working alliance ratings might have been influenced by their knowledge of participants' neuropsychological test results. A further methodological limitation of this study is the limited sample size, resulting in limited statistical power. Although social cognition impairments are common sequelae of the main subtypes of acquired brain injury, the identification of pre-injury mental health difficulties by 24% of the sample may be an influence on the social cognition profiles of participants in this study, even if exacerbated by the injuries themselves (and consequently the therapeutic working alliance with clinicians). Finally, the actual duration of therapeutic relationship between each informant and survivor was not quantified on an individual basis, complicated in part by the inter-disciplinary structure of the clinical services involved in the study.

Therapeutic relationship duration may be a significant moderating variable, and should be investigated in future studies. The unique predictors of working alliance situated within differing rehabilitation therapist interventions should also be demarcated in future studies (e.g., the provision of a psychoeducation group in the Rowlands, Coetzer & Turnbull (2020) study, versus an exploratory psychotherapy intervention within a rehabilitation programme). In addition, future research on the relationship between social cognition and the therapeutic alliance should employ

prospective research designs and larger samples. Further research should also investigate the effectiveness of the therapeutic concepts mentioned above in dealing with and amending social cognition difficulties in the context of brain injury rehabilitation.

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REFERENCE LIST

- Anderson, M. I., Simpson, G. K., Morey, P. J., Mok, M. M., Gosling, T. J., & Gillett, L. E. (2009). Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): multi-group analysis. *Brain Inj*, *23*(12), 931-943. doi:10.3109/02699050903302336
- Bateman, A. W., & Fonagy, P. (2012). *The Handbook of Mentalization-Based Therapy in Mental Health Practice*. New York: American Psychiatric Publishing.
- Bechara, A., Damasio, A. R., Damasio, H., & Anderson, S. W. (1994). Insensitivity to future consequences following damage to human prefrontal cortex. *Cognition*, *50*(1-3), 7-15.
- Blair, R. J., & Cipolotti, L. (2000). Impaired social response reversal. A case of 'acquired sociopathy'. *Brain*, *123* (Pt 6), 1122-1141.
- Blonder, L. X., Pettigrew, L. C., & Kryscio, R. J. (2012). Emotion recognition and marital satisfaction in stroke. *J Clin Exp Neuropsychol*, *34*(6), 634-642. doi:10.1080/13803395.2012.667069
- Bordin, E. S. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research & Practice*, *16*(3), 252-260.
- Bowman, C. H., & Turnbull, O. H. (2004). Emotion-based learning on a simplified card game: the Iowa and Bangor Gambling Tasks. *Brain & Cogn*, *55*(2), 277-282. doi:10.1016/j.bandc.2004.02.009
- Burgess, P., & Shallice, T. (1997). *The Hayling and Brixton Tests; Test manual*. Bury St Edmunds: Thames Valley Test Company.
- Caetano, C., Christensen, A. L., Uzzell, B. P., & Christensen, A. L. (2000). The CRBI at the University of Copenhagen: A participant-therapist perspective. In *International handbook of neuropsychological rehabilitation* (pp. 259-271). Dordrecht: Kluwer.
- Channon, S., & Crawford, S. (2000). The effects of anterior lesions on performance on a story comprehension test: left anterior impairment on a theory of mind-type task. *Neuropsychologia*, *38*(7), 1006-1017.
- Channon, S., Pellijeff, A., & Rule, A. (2005). Social cognition after head injury: sarcasm and theory of mind. *Brain Lang*, *93*(2), 123-134. doi:10.1016/j.bandl.2004.09.002
- Christensen, A. L., Caetano, C., Stuss, D. T., Winour, G., & Robertson, I. H. (1999). Neuropsychological rehabilitation in the interdisciplinary team: The post- acute stage. In *Cognitive neurorehabilitation: A comprehensive approach* (pp. 188-200). New York: Cambridge University Press.
- Daisley, A., & Webster, G. (2009). Familial Brain Injury: Impact on and Interventions with Children. In *Psychological Approaches to Rehabilitation after Traumatic Brain Injury* (pp. 475-507): BPS Blackwell.
- Daniels-Zide, E., Ben-Yishay, Y., Uzzell, B. P., & Christensen, A. L. (2000). Therapeutic milieu day program. In *International handbook of neuropsychological rehabilitation* (pp. 183-193). Dordrecht: Kluwer.
- Delis, D., Kaplan, E., & Kramer, J. H. (1991). *Delis Kaplan Executive Function System (D-KEFS)*. San Antonio: Psychological Corporation.
- Dewey, M. (1991). Living with Aspergers syndrome. In U. Frith (Ed.), *Autism and Aspergers syndrome*. Cambridge: Cambridge University Press.
- Elsass, L., & Kinsella, G. (1987). Social interaction following severe closed head injury. *Psychol Med*, *17*(1), 67-78.
- Evans, C. C., Sherer, M., Nakase-Richardson, R., Mani, T., & Irby Jr, J. W. (2008). Evaluation of an interdisciplinary team intervention to improve therapeutic alliance in post-acute brain injury rehabilitation. *The Journal of head trauma rehabilitation*, *23*(5), 329-338.

- Fluckiger, C., Del Re, A. C., Wampold, B. E., Symonds, D., & Horvath, A. O. (2012). How central is the alliance in psychotherapy? A multilevel longitudinal meta-analysis. *J Couns Psychol*, 59(1), 10-17. doi:10.1037/a0025749
- Frith, C. D., & Wolpert, D. M. (2004). *The Neuroscience of Social Interaction: Decoding, Imitating and influencing the actions of others*. Oxford, UK: Oxford University Press.
- Gervasio, A. H., & Kreutzer, J. S. (1997). Kinship and family members' psychological distress after traumatic brain injury: A large sample study. *Journal of Head Trauma Rehabilitation*, 12(3), 14-26.
- Godwin, E. E., Kreutzer, J. S., Arango-Lasprilla, J. C., & Lehan, T. J. (2011). Marriage after brain injury: review, analysis, and research recommendations. *J Head Trauma Rehabil*, 26(1), 43-55. doi:10.1097/HTR.0b013e3182048f54
- Henry, W. P., Strupp, H. H., Horvath, A. O., & Greenberg, L. S. (1994). The therapeutic alliance as interpersonal process. In *The working alliance: Theory, research and practice* (pp. 51-84). New York: Wiley.
- Hornak, J., Bramham, J., Rolls, E. T., Morris, R. G., O'Doherty, J., Bullock, P. R., & Polkey, C. E. (2003). Changes in emotion after circumscribed surgical lesions of the orbitofrontal and cingulate cortices. *Brain*, 126(Pt 7), 1691-1712. doi:10.1093/brain/awg168
- Horvath, A. O., & Symonds, B. D. (1991). Relation Between Working Alliance and Outcome in Psychotherapy - A Metaanalysis. *Journal of Counseling Psychology*, 38(2), 139-149.
- IBM_Corp. (2013). *IBM SPSS Statistics for Windows, Version 22.0*. Armonk: IBM Corp.
- Judd, D., & Wilson, S. L. (2005). Psychotherapy with brain injury survivors: An investigation of the challenges encountered by clinicians and their modifications to therapeutic practice. *Brain Injury*, 19(6), 437-449.
- Klonoff, P. S. (2015). Dilemmas and Innovations in Team Dynamics for Modern Holistic Milieu Therapy: A Thirty-Year Retrospective Review. *Neuro-Disability & Psychotherapy*, 3(2), 93-127.
- Klonoff, P. S., Lamb, D. G., & Henderson, S. W. (2001). Outcomes from milieu-based neurorehabilitation at up to 11 years post-discharge. *Brain Inj.*, 15(5), 413-428.
- Klonoff, P. S., Olson, K. C., Talley, M. C., Husk, K. L., Myles, S. M., Gehrels, J. A., & Dawson, L. K. (2010). The relationship of cognitive retraining to neurological patients' driving status: the role of process variables and compensation training. *Brain Inj*, 24(2), 63-73. doi:10.3109/02699050903512863
- Lewis, L. (1999). Transference and counter-transference in psychotherapy with adults having traumatic brain injury. In K. G. Langer, L. Laatsch, & L. Lewis (Eds.), *Psychotherapeutic Interventions for Adults with Brain Injury or Stroke: A Clinician's treatment Resource* (pp. 113-130). Madison: Psychology Press.
- Martin, D. J., Garske, J. P., & Davis, M. K. (2000). Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. *J.Consult Clin.Psychol.*, 68(3), 438-450.
- McDonald, S., Flanagan, S., Rollins, J., & Kinch, J. (2003). TASIT: A new clinical tool for assessing social perception after traumatic brain injury. *J Head Trauma Rehabil*, 18(3), 219-238.
- Niemela, M., Kinnunen, L., Paananen, R., Hakko, H., Merikukka, M., Karttunen, V., . . . Rasanen, S. (2014). Parents' traumatic brain injury increases their children's risk for use of psychiatric care: the 1987 Finnish Birth Cohort study. *Gen Hosp Psychiatry*, 36(3), 337-341. doi:10.1016/j.genhosppsy.2013.12.012
- Ponsford, J., & Schönberger, M. (2010). Family functioning and emotional state two and five years after traumatic brain injury. *J Int Neuropsychol Soc*, 16(2), 306-317. doi:10.1017/S1355617709991342
- Prigatano, G. P., Klonoff, P. S., O'Brien, K. P., Altman, I. M., Amin, K., & Chiapello, D. (1994). Productivity after neuropsychologically oriented milieu rehabilitation. *Journal of Head Trauma Rehabilitation*, 9, 91-102.
- Robertson, I., Nimmo-Smith, I., Ward, T., & Ridgeway, V. (1994). *Test of Everyday Attention*. Bury St. Edmunds: Thames Valley Test Company.

- Robertson, K., & Schmitter-Edgecombe, M. (2015). Self-awareness and traumatic brain injury outcome. *Brain Inj*, 29(7-8), 848-858. doi:10.3109/02699052.2015.1005135
- Rowlands, L., Coetzer, R., & Turnbull, O. H. (2020). Building the bond: Predictors of the alliance in neurorehabilitation. *NeuroRehabilitation*, 46(3), 271-285.
- Salas, C. E., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. A. J. (2016). "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychol Rehabil*, 1-18. doi:10.1080/09602011.2016.1247730
- Schönberger, M., Humle, F., & Teasdale, T. W. (2006a). The development of the therapeutic working alliance, patients' awareness and their compliance during the process of brain injury rehabilitation. *Brain Injury*, 20(4), 445-454.
- Schönberger, M., Humle, F., & Teasdale, T. W. (2006b). Subjective outcome of brain injury rehabilitation in relation to the therapeutic working alliance, client compliance and awareness. *Brain Injury*, 20(12), 1271-1282.
- Schönberger, M., Humle, F., & Teasdale, T. W. (2007). The relationship between client's cognitive functioning and the therapeutic working alliance in post-acute brain injury rehabilitation. *Brain Injury*, 21(8), 825-836.
- Schönberger, M., Humle, F., Zeeman, P., & Teasdale, T. W. (2006a). Patient compliance in brain injury rehabilitation in relation to awareness and cognitive and physical improvement. *Neuropsychological Rehabilitation*, 16(5), 561-578.
- Schönberger, M., Humle, F., Zeeman, P., & Teasdale, T. W. (2006b). Working alliance and patient compliance in brain injury rehabilitation and their relation to psychosocial outcome. *Neuropsych Rehabil*, 16(3), 298-314.
- Schönberger, M., & Ponsford, J. (2010). The factor structure of the Hospital Anxiety and Depression Scale in individuals with traumatic brain injury. *Psychiatry Res*, 179(3), 342-349. doi:10.1016/j.psychres.2009.07.003
- Schönberger, M., Ponsford, J., Olver, J., & Ponsford, M. (2010). A longitudinal study of family functioning after TBI and relatives' emotional status. *Neuropsychol Rehabil*, 20(6), 813-829. doi:10.1080/09602011003620077
- Sherer, M., Evans, C. C., Leverenz, J., Stouter, J., Irby, J. W., Lee, J. E., & Yablon, S. A. (2007). Therapeutic alliance in post-acute brain injury rehabilitation: Predictors of strength of alliance and impact of alliance on outcome. *Brain Injury*, 21(7), 663-672.
- Stagg, K., Douglas, J., & Iacono, T. (2017). A scoping review of the working alliance in acquired brain injury rehabilitation. *Disabil Rehabil*, 1-9. doi:10.1080/09638288.2017.1396366
- Struchen, M. A., Pappadis, M. R., Sander, A. M., Burrows, C. S., & Myszka, K. A. (2011). Examining the contribution of social communication abilities and affective/behavioral functioning to social integration outcomes for adults with traumatic brain injury. *J Head Trauma Rehabil*, 26(1), 30-42. doi:10.1097/HTR.0b013e3182048f7c
- Wechsler, D. (1997). *Wechsler Memory Scale-Third Edition manual*. San Antonio: The Psychological Corporation.
- Whelan-Goodinson, R., Ponsford, J., & Schönberger, M. (2009). Validity of the Hospital Anxiety and Depression Scale to assess depression and anxiety following traumatic brain injury as compared with the Structured Clinical Interview for DSM-IV. *Journal of Affective Disorders*, 114(1-3), 94-102.
- Wilson, B. A., Emslie, H., Evans, J., Alderman, N., & Burgess, P. (1996). *Behavioural Assessment of the Dysexecutive Syndrome (BADS)*. San Antonio: Pearson Clinical.
- Yeates, G. N. (2013). Towards the neuropsychological foundations of couples therapy following acquired brain injury (ABI): A review of empirical evidence and relevant concepts. *Neuro-Disability & Psychotherapy*, 1, 108-150.
- Yeates, G. N. (2014). Social cognition interventions in neuro-rehabilitation: An overview. *Advances in Clinical Neuroscience & Rehabilitation*, 14(2), 12-13.
- Yeates, G.N., Hamill, M., Sutton, L., Psaila, K., Mohamed, S & O'Dell, J. (2008). Dysexecutive problems and interpersonal relating following frontal brain injury: Reformulation in Cognitive-Analytic Therapy. *Neuro-Psychoanalysis*, 10(1), 43-58.

Yeates, G. N., Rowberry, M., Dunne, S., Goshawk, M., Mahadevan, M., Tyerman, R., . . . Tyerman, A. (2016). Social cognition and executive functioning predictors of supervisors' appraisal of interpersonal behaviour in the workplace following acquired brain injury. *NeuroRehabilitation*, 38(3), 299-310. doi:10.3233/NRE-161321

Zelencich, L., Kazantzis, N., Wong, D., McKenzie, D., Downing, M., & Ponsford, J. (2020). Predictors of working alliance in cognitive behaviour therapy adapted for traumatic brain injury. *Neuropsychological rehabilitation*, 30(9), 1682-1700.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.

A MIXED METHODS PILOT STUDY OF A 6 MONTH WEEKLY TAI JI (TAI CHI) GROUP FOR SURVIVORS OF ACQUIRED BRAIN INJURY.

UN ESTUDIO PILOTO DE MÉTODOS MIXTOS DE UN GRUPO DE TAI JI (TAI CHI) SEMANAL DE 6 MESES DE DURACIÓN PARA SUPERVIVIENTES DE LESIONES CEREBRALES ADQUIRIDAS.

YEATES, GILES*¹; SMITH, ALISON²; NAGRANI, SONAM³; KHAN, EACHELLE³; DORNEY-SAVAGE, JENNY³

* Correspondencia:
Yeates Giles
drgilesyeates@gmail.com

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Physical and psychological benefits of tai chi (TJ) have been demonstrated for survivors of acquired brain injury (ABI). However investigators have framed TJ primarily as a physical intervention, with an absent underlying theoretical framework to conceptualise psychological gains from the practice. Traditional sampling strategies have optimised homogenous samples in many studies, in contrast to ABI groups with diverse physical, cognitive and emotional needs that commonly use community-based ABI services. This study aims to use both qualitative and quantitative methods to highlight both shared gains and diversity in responses to a standard TJ group intervention in a typical ABI community service sample. These preliminary findings will be used to develop a rationale for bespoke adaptation of TJ learning/practice to optimise psychological gains across survivors. 9 Survivors of ABI using community services were recruited to attend a weekly class of TJ over six months. The instructor offered some physical adaptations to learning and practice. Questionnaire measures of anxiety/depression, fatigue and QoL were administered at baseline, repeated every 4 sessions and at the end of the last session. A focus group was held half-way and at the end of the intervention. Quantitative data was analysed using single-case pre-post comparisons (RCI), and a thematic analysis was performed on the qualitative data. While clinical gains in reduced anxiety, depression and fatigue and improved QoL was observed for some participants, no changes or deterioration on some measures were evident in others. Focus group data highlighted shared gains in increased energy, relaxation and social group identification, alongside idiosyncratic challenges for each participation from the class environment, cognitive and physical demands of learning TJ. This study has provided both quantitative and qualitative data which highlight diverse experiences and challenges for survivors of ABI when learning and practicing TJ, although there are also indications of shared benefits in fatigue management and social group membership.

Se han demostrado los beneficios físicos y psicológicos del tai chi (TJ) para los sobrevivientes de una lesión cerebral adquirida (LCA). Este estudio pretende utilizar métodos cualitativos y cuantitativos para poner de relieve tanto los beneficios compartidos como la diversidad de respuestas a una intervención grupal estándar de TJ en una muestra típica de servicios comunitarios de LCA. Estos resultados preliminares se utilizarán para desarrollar una justificación para la adaptación a medida del aprendizaje/práctica de TJ para optimizar los beneficios psicológicos. 9 sobrevivientes de LCA que utilizan los servicios comunitarios fueron reclutados para asistir a una clase semanal de TJ durante seis meses. El instructor ofreció algunas adaptaciones físicas para el aprendizaje y la práctica. Se administró un cuestionario de ansiedad/depresión, fatiga y calidad de vida al inicio, repetido cada 4 sesiones y al final de la última sesión. Se realizó un grupo de discusión a mitad y al final de la intervención. Los datos cuantitativos se analizaron mediante comparaciones pre-post (RCI), y se realizó un análisis temático de lo cualitativo. Mientras que en algunos participantes se observaron ganancias clínicas en la reducción de la ansiedad, la depresión y la fatiga, así como una mejora de la calidad de vida, en otros no se observaron cambios o hubo un deterioro en algunas medidas. Los datos del focus group resaltaron aumento compartido en incremento de energía, relajación e identificación de grupo social, junto con retos idiosincráticos para cada participación desde el entorno de la clase y demandas cognitivas y físicas de aprender TJ. Este estudio ha proporcionado datos cuantitativos y cualitativos que ponen de relieve las diversas experiencias y desafíos para los sobrevivientes de LCA cuando aprenden y practican TJ.

Palabras claves: Tai Chi, Tai Ji; Qi Gong; Meditación; Lesión Cerebral; Métodos mixtos; Comunidad; Rehabilitación.

Keywords: Tai Chi; Tai Ji; Qi Gong; Meditation; Brain Injury; Stroke; Mixed Methods; Community; Rehabilitation.

¹Centre of Movement, Occupation & Rehabilitation Sciences (MORes), Oxford Brookes University

²Tai Chi for Everyone, Buckinghamshire

³Community Head Injury Service, Buckinghamshire Healthcare NHS Trust

INTRODUCTION:

Adult survivors of acquired brain injury (ABI, e.g., traumatic brain injury, stroke, hypoxia, infection, post-tumour resection, toxicity) often experience enduring difficulties in multiple domains of functioning (physical, cognitive, emotional, social) simultaneously. The specific combination and constellation of difficulties across these domains will vary significantly across survivors as a function of lesion location, underlying neuropathology, premorbid vulnerabilities and post-injury factors. These complicated needs are situated within a wider context of diminishing service provision and support available within community settings over time. Some survivors of ABI report profound disruptions to identity and self-experience, such as being 'in fragments' (Nochi, 1997), living in a 'shattered world' (Luria, 1979), experiencing a pendulum identity of function to dysfunction (Charmaz, 1990) and living as 'a shell of a person' (Yeates, 2019 a,b,c).

There is a need therefore, for community-based interventions that simultaneously focus on physical and psychological needs, and also confer the psychosocial benefits of community leisure group membership noted for survivors of ABI (Haslam et al., 2008). In actuality, in many countries of the world, physical, psychological and social interventions are offered in isolation from one another, uninformed by the other, and all within time-limited durations that are not commensurate with the enduring nature of post-injury difficulties (DoH, 2005).

Given these trends, there is a current interest in the application of Eastern mind-body interventions within neuro-rehabilitation, such as mindfulness meditation (Johansson et al., 2012) and yoga (Yeates et al., 2015). These approaches have been associated with both physical and psychological benefits for survivors, and are suited to be offered on a longer-term basis in a community setting. An additional approach that has been subject to many investigations in the ABI literature is Tai Ji (Tai Chi, hereon abbreviated as TJ). TJ is characterised by slow, fluid movements, regulated breathing and a diminution of self-reflective experience. The historical background, cultural and theoretical framework of TJ is provided in Yeates (2015; 2019a). Within ABI, both physical and psychological benefits of TJ for survivors of traumatic brain injury have been reported in small group studies and anecdotal case reports (Blake & Batson, 2006; Gemmell & Leatham, 2006; Yeates, 2019 a,b,c). The evidence is strongest for stroke survivors, where across large group studies and highlighted

in several meta-analyses, TJ has been shown to be a safe practice (Taylor-Piliae & Coull, 2012; Winser et al., 2018), and produce replicable gains in balance, mobility, falls reduction, plus reduction in fatigue, anxiety and low mood (Lyu et al., 2018; Zheng et al., 2016). TJ is therefore supported as one promising modality of support and participation, to simultaneously address the physical and psychological needs of survivors following differing forms of ABI. Future studies using robust research methodologies are awaited for ABI subtypes other than stroke.

While there is an encouraging basis for recommending the use of TJ with ABI, there are limitations to extending the results of these studies to the aforementioned group of service users who have complex needs spanning multiple domains. Firstly, some of the stroke studies actively screen out survivors with comorbid cognitive impairment (e.g., Taylor-Piliae et al., 2014). Few authors have outlined how the learning and ongoing practice of TJ is adapted for physical disabilities such as vestibular problems, hemiplegia, or bilateral lower limb immobility (Hwang et al., 2017, being an exception). While these trends are consistent with conventional sampling and protocol strategies to optimise homogeneity within study samples, this approach puts the resultant data adrift from many users of ABI services. In a similar vein, the evaluation of brief TJ group durations (commonly 4-6 weeks, Yeates, 2015) in a post-acute hospital setting limits expectations of the impact of a longer-term group in a community setting, which is closer to how the majority of TJ is taught and practiced in the general population. Furthermore, the development of a knowledge-base of necessary adaptation of TJ learning and practice in response to both physical and cognitive needs is not stimulated by a current absence of relevant preliminary data.

Furthermore, the conceptualisation of the relationship between TJ practice and mental wellbeing in practitioners following ABI is absent. TJ has been studied and reported primarily as a physical intervention for balance and mobility in stroke survivors, although secondary outcomes such as improvements in fatigue, anxiety and depression have also been noted (see reviews by Lyu et al., 2018). While improvements in physical functioning will undoubtedly be associated with positive mental wellbeing, TJ has been shown to produce a positive effect on psychological outcomes over matched exercise programs (Zheng et al., 2016).

Few frameworks have been postulated in the ABI TJ evaluation studies to account for this relationship. In a TJ

study on people with multiple-sclerosis, Burschka and colleagues (2014) have used a mindfulness framework to conceptualise the effect of TJ on psychological health, and some mindfulness stroke studies have indeed used TJ and related qi gong movements within their intervention protocols. Yeates (2015; 2019 a,b,c) has argued that the concept of flow state experience (Csíkszentmihályi, 1990; 1997 – a reduction of self-analytical experience whilst immersed in a particular activity) is a closer fit with the spiritual frameworks in Daoism, which guides TJ practice for many masters in China who use this for holistic development and cultivation, encompassing, physical, psychological and spiritual dimensions of experience. Hung and colleagues (2021) have found support for a useful overlap of Flow dimensions and those in the embodied experience of TJ and related Chinese mind-body practices.

Yeates (2015; 2019 a,b,c) has advocated that this lens on TJ practice can be used to apply such to a wide range of survivor needs (including making TJ a potential element of the underdeveloped scope of neuro-rehabilitation for users' spiritual needs). In addition, Yeates has argued that the same framework can be used to direct the adaptation of TJ learning and practice in a bespoke fashion to survivors' unique constellation of physical, cognitive, emotional and social needs.

A programme of accumulated evidence for such an approach to adaptation is arguably subsequent to initial data that demonstrates the significance of survivor diverse needs for the implementation of a standardised, unadapted TJ intervention that is commonly used in the ABI TJ literature. The primary aim of this paper is to report on such an intervention. Specifically, the authors wanted to make it relevant to a longer-term community setting, in which it is argued that TJ is ideally-placed. As such, we are reporting on a weekly TJ group of 6 months (24 sessions in duration). Given the previous omissions in the ABI TJ literature, fatigue and psychological outcomes are of primary interest.

To explore diversity in needs within a typical community ABI sample, no selective or matching sampling criteria were used (see method, below, for more details). In addition, the data from the recruited group of participants with diverse physical, cognitive and emotional needs were not aggregated within a group comparison analysis. Instead, the rich nuances of similarities and differences in impact of TJ participation on the sample was subject to both a single case quantitative analysis and a qualitative focus group

methodology within a mixed methods design. Both types of data were used in a manner appropriate to the limitations of each, and also triangulated to inform the other as an approach to study the impact of survivor diversity in needs on TJ practice (and the benefits or otherwise gained from this practice). To date, three case studies with positive outcomes (Yeates, 2019 a,b,c) have been published from this sample, which have been used to illuminate an underlying theoretical framework underpinning TJ practice following ABI. Here we report data from the whole sample, noting all trends that can be conservatively identified given the limitations of the data.

METHOD:

2.1. Recruitment & Service Context:

Recruitment posters were posted in three community organisations that support survivors of ABI in the community within the county of Buckinghamshire in the UK: The Community Head Injury Service (CHIS, Buckinghamshire Healthcare NHS Trust), the Buckinghamshire Community Neurological Rehabilitation Team (CNRT) and Enrych Bucks. All services provide long-term support for survivors of ABI, and follow a social model of support. CNRT and CHIS are health-based rehabilitation services. In addition, CHIS offers multi-disciplinary community rehabilitation support over a long-duration of time and is organised by a social model of disability (Tyerman, 1999). CHIS and CNRT refer many of its users to Enrych Bucks, a third sector charitable organisation, to access ongoing leisure and socialising opportunities with other survivors of ABI and other disabilities in the Buckinghamshire area.

Service users of all three services were made aware of the TJ group via an information poster and signposting by keyworkers. As such, those who elected to attend the group were representative of survivors of ABI in the community, who would find TJ a meaningful opportunity to work within a group setting on their physical and mental health needs, learn a new skill and meet new people (consistent with the replicated outcomes of TJ participation published in the literature).

Survivors of ABI using these services are typically 16 years plus in age, 1 year post-injury or greater, and have sustained a traumatic brain injury, stroke, infection, hypoxia or post-tumour resection. They commonly are managing multiple domains of post-injury sequelae, including physical, cognitive, emotional and social difficulties.

2.2. Tai Ji Group Format:

The group was conducted in a church hall within a suburb of Aylesbury, UK. Participants were provided with hospital transport to the venue, or made their own way to each session. 24 sessions were held over 6 months. Each session was 90mins in duration, and included a first 40 minute section of warm-up exercises and tai ji form practice, all learned and performed together as a group. Then a tea break and socialising opportunity was included, lasting 20-30 minutes. This left a final section of 20-30 minutes for further form practice and cool-down exercises. The main Tai Ji form used was taken from Paul Lam's tai ji for health conditions syllabus, which is accessible to learn from a cognitive perspective and includes versions for those standing and chair-based. There was no requirement for participants to practice the movement in between the weekly sessions.

As such, the option of performing the movements while standing or seated represented one generic adaptation of TJ for those with physical restrictions. Repetition and a slow pace of learning was a parallel adaptation for cognitive needs. One participant spontaneously recorded a video of the learning content on his phone, so support his decision to practice at home. However no other bespoke adaptation were made by the organisers, for specific vestibular, dyspraxia, sensory or modality-specific cognitive difficulties, such as those suggested by Yeates (2015; 2019 a,b,c) were included.

2.3. Participants

Ten survivors responded to the recruitment process from the 3 participating services, and nine of these participated in the sessions. The demographics and injury-related data of the sample are summarised in table 1 below.

Typical of ABI service users, the majority (89%) were male. There is a range of ages and the range of time post-injury highlights participants as representative of users of long-term community services, the target of our TJ intervention. Four different forms of acquired brain injury are represented: ischaemic and haemorrhagic stroke; traumatic brain injury and post-tumour resection surgery. The sample fulfilled our aims of having a heterogenous sample for disability type, as diverse forms and combinations of physical, cognitive and emotional needs were evident across participants (this information gained from a combination of clinical interviews, standardised questionnaire assessment and standardised cognitive and physical ability assessment as part of the recruiting services' core clinical activities).

No participant had significant experience of TJ prior to the study - two participants had previously tried classes for the general population, but not continued. The difficulties in physical, cognitive, emotional and social domains highlighted for each participant were identified using both formal physiotherapy and neuropsychological standardised tests in the clinical services, and also self-report by survivors.

2.4. Analysis

Given the small numbers of participants, a mixed-methods methodology was used to generate rich data and inform the design of future studies. Firstly, each participant completed a range of self-report standardised questionnaires on mood, fatigue and quality of life, prior to the first TJ session and following the last session. These measures are reported below. Single case pre-post quantitative comparison was undertaken to assess statistically-reliable change (using the Reliable Change Index, Jacobson & Truax, 1992) The clinical significance of any statistically-significant, reliable change is indicated by an improved score passing a cut-off threshold for healthy functioning as specified in the literature.

In addition, participants completed a focus group interview, a) half-way through the intervention and also b) following the last session. Details are provided below. The qualitative data derived from both focus groups was analysed using thematic analysis (ref). Both the questionnaires and focus groups were administered by assistant psychologists (SN and EK) in a research role, who did not deliver the TJ group itself. The small participant numbers did not permit a group analysis.

2.4.1. Standardised Questionnaire Measures

Anxiety and depression for survivors of ABI was measured using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), noted for its sensitivity to mood difficulties following ABI independent of non-mood related post-injury changes. Fatigue was assessed using the Modified Fatigue Impact Scale (M-FIS, Fisk et al., 1994), which yields a total fatigue score, plus subscores for physical, cognitive and psychosocial fatigue. These measures were administered before the first session, after the last session, and every 4 weeks during the 6 month duration of the classes. In addition participants completed a Quality of Life (Quality of Life after Brain Injury Inventory, QOLIBRI, Von Steinbüchel et al. 2010) at the

Table 1: Participant Demographics

Participant	Gender	Age	Injury Type	Time Post-Injury (years)	Physical Impairments	Cognitive Deficits	Psychosocial Needs
Raymond	M	48	Haemorrhagic RMCA Stroke	4	Left hemi-paresis involving lower and upper limbs Mobility restrictions (wheelchair user) Fatigue	Initiation Planning & organising Attention Left visual neglect	Anxiety Separation with wife Social isolation
Andy	M	44	Ischaemic LMCA Stroke	6	Right hemi-paresis involving lower and upper limbs Fatigue	Expressive aphasia Attention Memory Formation of goals when planning	Low mood Anxiety Social isolation Substance dependency
Mark	M	44	Tumour resection (involving right temporal lobe & cerebellum); post-operative CSF leak and meningitis	17	Balance Fatigue	Speed of information processing Selective attention Sustained Attention Working memory Cognitive flexibility Goal-directed planning	Anxiety Obsessive-Compulsive Disorder Relationship strain with partner Social isolation
Neal	M	65	Ischaemic RMCA Stroke	7	Balance Bilateral sensory loss in fingers Fatigue	Speed of information processing Attention Memory Ideomotor dyspraxia Executive functioning	Anxiety Depression Anger Relationship strain with wife and adult children Social isolation
Bill	M	64	Ischaemic RMCA Stroke	5	Left hemi-paresis involving lower and upper limbs Mobility restrictions (wheelchair user) Fatigue	Initiation Planning & organising Attention Memory Left visual neglect	Low mood Anxiety Social isolation
Roger	M	28	Space-occupying cyst in childhood	25	None	Memory Executive functioning (goal formation and implementation) Social cognition (emotion recognition, mentalising, social inference)	Social anxiety Social isolation Breakdown of relationships in the community and workplace
Dale	M	56	Ischaemic RMCA Stroke		Left hemi-paresis involving lower and upper limbs Mobility restrictions (wheelchair user) Fatigue	Speed of information processing Attention Implementation of plans Left visual neglect	Low mood Anxiety Separation with wife Relationship strain with children Social isolation
Seema	F	35 28	Sub-arachnoid Haemorrhage		Balance Fatigue	Speed of information processing Attention Working memory Cognitive flexibility	Anxiety Worry/rumination Anger/frustration Depression Social isolation Strained relationships with others, including professionals
Simon	M	55	Traumatic Brain Injury (Right Frontal Contusions, GCS 5/15)		None	Attention Initiation Planning and organising Social cognition (emotion recognition)	Anxiety Social isolation Breakdown of relationships in the community and workplace

first and final time point only. A sub-set of these measures were completed by participants once a month for the duration of the six month group, to enable visual plotting of trends over time (see results).

Participant scores on the questionnaires were not shared in the whole group or in the focus group sessions. Where clinical levels of psychological distress were identified, individual participants were offered an opportunity to speak to a key psychological practitioner within their respective clinical services.

2.4.2. Focus Group Interviews

The interview consisted of open-ended and follow-up focused questions exploring participants' experiences of attending the sessions, the learning process, experienced gains/benefits, experienced barriers, and the social dimension of group attendance. The interview process was adapted for participants' cognitive and communication deficits, following the guidelines of Patterson & Scott-Findlay (2002). The collected data was analysed using Thematic Analysis (Braun & Clarke, 2006), which involved line by line coding of transcripts, and these codes collated and contrasted within higher-order salient themes, that reflected the face content of participants' responses (in contrast to a theoretical or interpretive-focused qualitative analytical approach). All participants were anonymised and any personally-identifiable places, names or other biographical information was changed to protect participant confidentiality.

RESULTS:

3.1. Participant Retention

Of the 9 participants that started the TJ group 3 (33%) had stopped attending by the end of two months. Reasons cited were focused on difficulties travelling to the venue and clashes with medical appointments. The remaining 6 participants (66%) completed an average of 80% (range 50-92%) of the 24 (6 months) of classes, with occasional sessions missed due to illness and holidays.

3.2. Self-Report Questionnaires

The questionnaire total scores for all 9 participants who started the study are highlighted in Table 2, along with session attendance. These scores are those measured pre-TJ group and at the same time point a week after the TJ group, for all of the original 9 participants. Changes in total pre-post scores are indicated, together with the direction, statistical-reliability and clinical significance of any change.

Of those changes that were identified as statistically-reliable using Jacobson and Truax's (1991) Reliable Change Index method, 2 participants demonstrated reduced levels of fatigue on the MFIS (Raymond and Bill, with Bill's clinically-significant reduction in scores moving from the clinical to the normal range), and 1 participant demonstrated reliable and clinically-significant reduced levels of depression symptomatology on the HADS depression scale (Andy, whose scores passed from the moderate to normal range). 1 participant's (Bill) scores on the QoLiBri reliably improved.

There were no reliable changes for any participants on measures of anxiety. 4 participants demonstrated no reliable changes on any measures, all of whom had attended 50% or less of the sessions. Two participants demonstrated a negative trajectory across the duration of the TJ group, with depression scores on the HADS increasing from the sub-clinical (Neal) and mild (Mark) ranges to the moderate range.

Given the variability in pre-post change on all measures across the participants, trends in changing scores on the HADS and MFIS every 4 weeks over time for the 5 participants who attended the majority of TJ sessions over the six months. The scores for HADS Anxiety, HADS Depression, MFIS Total, MFIS Physical subscale, MFIS Cognitive subscale and MFIS psychosocial subscale are graphed in figures 1-6 below.

There is significant spread and diversity in the trajectory of scores for each measure across the 5 participants. The MFIS Physical Subscale score trajectories demonstrate a greater level of uniformity relative to the other measures, with indications of a decreasing trend in scores for most participants.

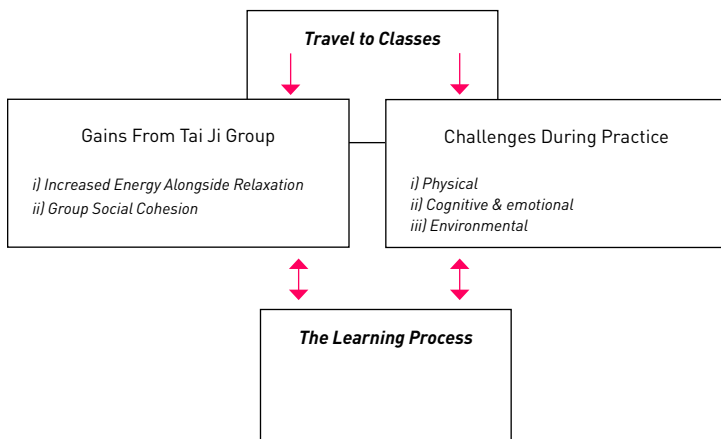
3.2. Qualitative Thematic Analysis of Focus Group Interviews

All participants within the focus groups were happy to complete each session. Using the methodology suggested by Braun and Clarke (2006), the thematic analysis of the interview data from both the mid-intervention focus group (7 participants: Raymond, Andy, Mark, Neal, Bill, Roger, Seema) and the post-intervention focus group (6 participants: Raymond, Andy, Mark, Neal, Bill, Roger) yielded the following superordinate and subordinate themes: *benefits of group participation* (including *i) increased energy alongside relaxation; ii) group social cohesion*); *challenges during practice* (including *i) physical; ii) cognitive and emotional; iii) environmental*); *the learning process*; and *travel to classes* (represented in figure 7).

Table 2: Pre- & Post-Intervention Scores on Main Questionnaire Measures Per Participant

Participant	% Sessions Attended	HADS Pre	HADS Post	Pre-Post Diff (RCI)	MFIS Pre Total Subscales	MFIS Post Total Subscales	Pre-Post Diff (RCI)	QoLiBri T-Score Total Pre	QoLiBri T-Score Total Post	Pre-Post Diff (RCI)
Raymond	92	A 8 D 6	A 6 D 8	1.19 [^] -1.15 [^]	T 51 Ph 20 C 27 Ps 4	T 39 Ph 14 C 22 Ps 3	2.02*	60	59	0.13
Andy	88	A 9 D 11	A 9 D 6	0 2.88**^	T 60 Ph 35 C 17 Ps 8	T 51 Ph 30 C 19 Ps 2	1.52	29	44	0.65
Mark	71	A 17 D 7	A 14 D 12	1.79 [^] -2.88**^	T 67 Ph 28 C 31 Ps 8	T 64 Ph 25 C 32 Ps 7	0.51	80	79	-0.13
Neal	92	A 8 D 5	A 10 D 12	-1.19 -4.02**^	T 37 Ph 14 C 20 Ps 3	T 40 Ph 10 C 26 Ps 4	-0.51	57	48	-1.17
Bill	88	A 2 D 4	A 0 D 2	1.19 1.15	T 34 Ph 26 C 3 Ps 5	T 6 Ph 6 C 0 Ps 0	4.72**^	69	85	2.08*
Roger	50	A 8 D 5	A 8 D 6	0 -0.58	T 27 Ph 5 C 19 Ps 3	T 22 Ph 7 C 12 Ps 3	0.84 [^]	55	66	1.43
Dale	33	A 8 D 9	A 7 D 8	0.60 [^] -0.58	T 53 Ph 25 C 23 Ps 5	T 54 Ph 20 C 26 Ps 8	-0.16	49	na	na
Seema	25	A 14 D 13	A 17 D 13	-1.79 [^] 0	T 59 Ph 30 C 22 Ps 7	T 62 Ph 28 C 27 Ps 7	-0.51	37	na	na
Simon	16	A 9 D 17	A 7 D 14	1.19 [^] 1.72 [^]	T 71 Ph 34 C 29 Ps 8	T 64 Ph 24 C 33 Ps 7	1.18	39	na	na

Figure 7: Thematic Analysis Summary of Focus Group Interviews



These are summarised below with illustrative quotes from participants.

1. Benefits of Group Participation:

Participants identified important gains from attending the sessions for the mind, relaxation and wellbeing:

(First focus group):

Mark: "I think that tai chi in itself is actually good for you because of the breathing. The fact that you're, you know you're trying to do movements sort of smoothly and you're breathing smoothly and I think that really helps your mind. Yeah I think it's just good for it, your mind".

(Second focus group):

Mark: "it teaches you how to relax...if you can sit down and relax, it teaches you how to kind of ... let go and slow down"

Roger: "I did cricket training like, it's in the evening but I always feel after this ...just so relaxed

Neal: "it improves wellbeing I think, overall wellbeing"

Group: "yeah".

Mark: "I feel calmer after it"

Andy: "Yeah calmer"

Raymond: "I feel relaxed, yes, very relaxed"

Bill: "always looking forward to the next week"

Raymond: "It's the only day I get up with a purpose. It's the only day."

Roger: "it's sets you up for the rest of the week"

The specific gains clustered around two main benefits as a majority consensus for participants. First, several

participants described a simultaneous feeling of both increased energy following the sessions, alongside an experience of relaxation:

(First Focus Group):

Roger: "...I find it relaxing, it's really relaxing. Considering I will go from, after this I will go sit, chill out for about half an hour at home when I get back. I then feel like the motivation I can do, oh I can do the washing, I can do this, this and this. I can then go and do my shopping as well, so I feel better for it."

Neal: "Oh that's right yeah and erm I enjoy doing the form together as a group, as a whole. I find that quite energising. I don't know. I tend to get energy of the others as well."

Bill, who demonstrated a reliable, clinically-significant reduction in fatigue over the course of the intervention, noted a contradiction of being both tired but also revitalised:

Bill: "hmm yeah I said drained earlier but I did mean drained as well, but equally at the same time I know it's a bit of an opposite but I do feel re-invigorated with life. it's difficult to describe but it's both ends of the spectrum."

Secondly, a core dimension of gain endorsed by all participants was the social experience of attending – feeling close as a group, forging friendships and practicing together:

(second focus group):

Neal: "the social aspect is good"

Bill: "yes, a nice group of people"

Roger: "therapeutic"

Raymond: "and I feel that I've got half a dozen more friends than I had before, because I've only really got one friend and that's my girlfriend, so it is good...yeah"

2. Challenges During Practice:

In contrast to the benefits, participants diverged in identifying specific challenges to attending the group, with the exception of memory. The different challenges identified by participants have been organised under the headings of *physical*; *cognitive and emotional*; and *environmental* categories.

Physical challenges included fatigue for some, either alongside or in contrast to the energising benefits reported by others above:

(first focus group)

Bill: "... it is very tiring doing an hour's worth of tai chi"

Figure 1: HADS Anxiety Scores Per Participant Over the Duration of the Intervention

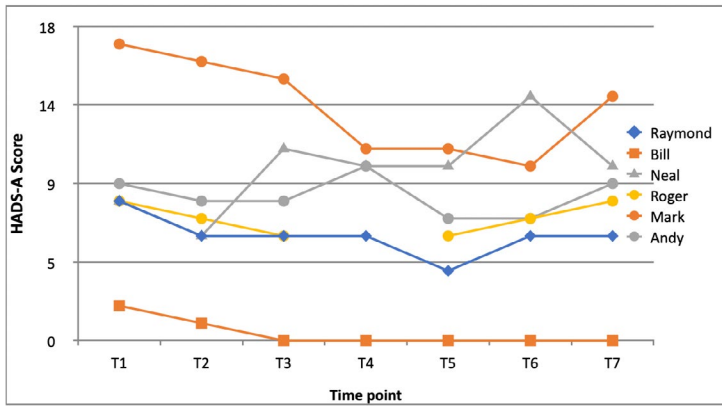


Figure 4: MFIS Scores Per Participant Over the Duration of the Intervention

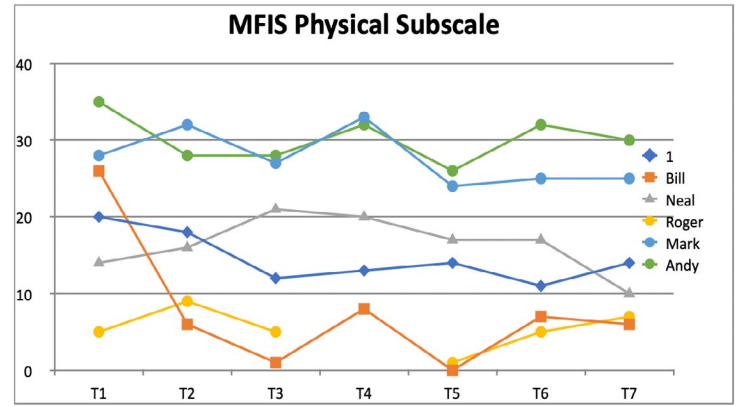


Figure 2: HADS Depression Scores Per Participant Over the Duration of the Intervention

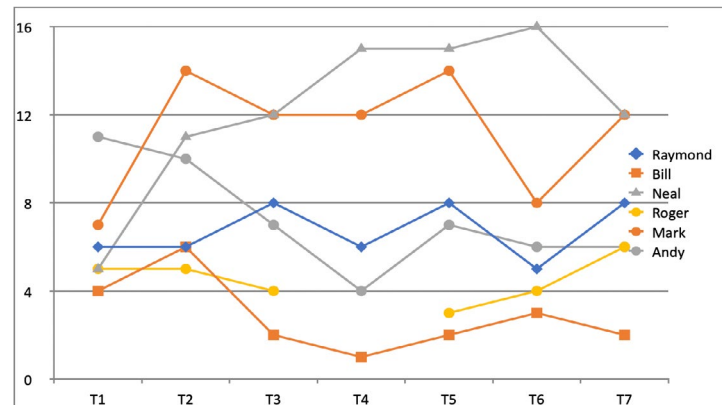


Figure 5: MFIS Scores Per Participant Over the Duration of the Intervention

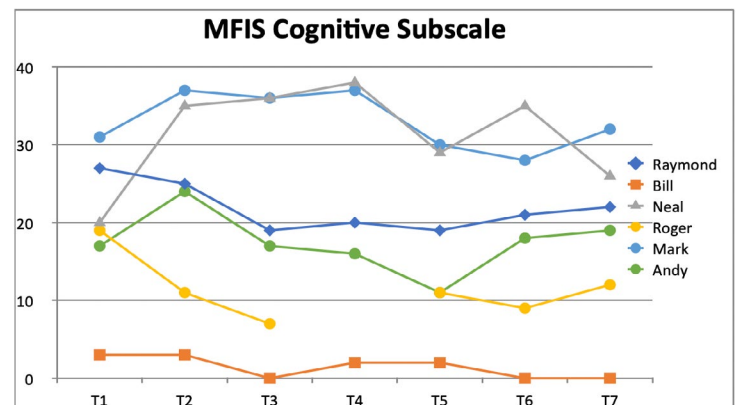


Figure 3: MFIS Scores Per Participant Over the Duration of the Intervention

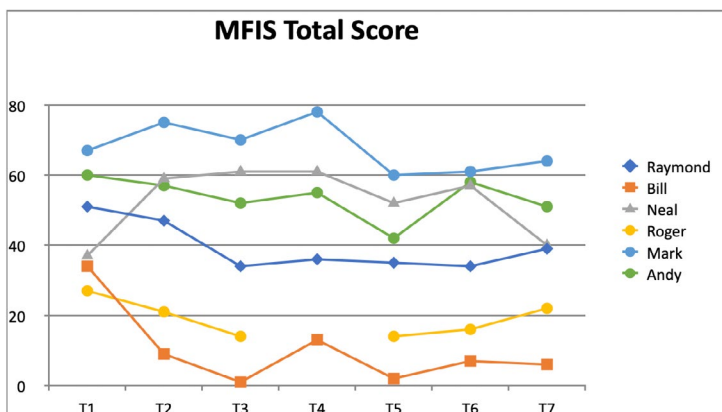
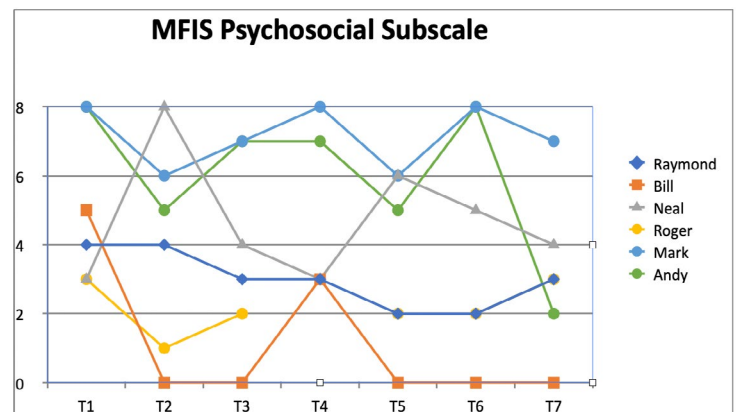


Figure 6: MFIS Scores Per Participant Over the Duration of the Intervention



Seema: “Oh yeah again like you were saying, because the session is so long I feel exhausted by the second half”

Mark: “Yeah I have to sleep for a bit when I get home before I can do anything. it’s taking on the information rather than the physical thing I think.”

Furthermore, there were unique challenges for participants with mobility restrictions during the sessions:

Bill: “For me, for me, sorry, yes. I mean being in a wheelchair, it’s more difficult for me because of that. And Raymond probably as well. But I do find it a bit limiting not being able to stand up and do any of the moves safely. But I do.... even though I’m sitting in the wheelchair trying to do as much as I can, I still really enjoy it and it’s a challenge.”

The internal dimensions of *cognition and emotion* were key also. There was greater consensus across participants on the influence of memory limitations on group experience:

(first focus group)

Andy: “Memory, yeah that’s the main thing”

Roger: “more complex moves, so that bit right at the end, going from that to that (gestures movements) I’m still trying to remember, am I doing it right and other than that it’s just time. I wish there was more time to do it, so if we had like an hour’s break and two hours of tai chi just to try and save.... not too tight”

(Second focus group)

Bill: “I found it, as I said before, it is quite a long form that we have to learn. I found it quite challenging to remember the form.”

Neal: “yeah I think it’s just learning the form ... I can’t bloody learn it”

Interviewer: You mean the memory aspect of it?

Neal: “yeah, yeah”

Roger: “pretty much the same, it’s just remembering it, remembering all of the sequence”.

An additional cognitive challenge identified by the group was information processing and concentration for the new material that was least familiar at the beginning of the 6 months group:

Bill: “It’s got very much more intense, I mean as we’ve gone over the last, over the sessions and it’s been added to and added to, I have found it very very difficult to keep up with it

sometimes and sometimes when it goes a bit too quick I lose out on the middle bits – erm I get lost.”

Andy: “...much better I think – erm before I was a bit slow and oh that’s not right, that’s not right but I remembered so.”

Neal: “But the only concern I have is if the group ever got any bigger that there would be too much going on in the room to be able to concentrate on what I need to concentrate on, which is the instructor.”

These challenges were not raised at the end of the 6 months. Emotional challenges within the early phase of TJ group participation were identified by two of the participants:

(first focus group):

Roger: “Mines more of a frustration. I wish I could do more in the time that I had.”

Andy: “I was very, very nervous. People I don’t know. it’s helped me, it’s a lot ... I liked it and I still like it now.”

The final challenge within the classes identified by some was the physical environment, specifically the temperature and acoustics of the hall in which the TJ classes were being provided:

(first focus group):

Seema: “that is such a massive hindrance because since my brain injury I no longer have the ability to block out background noise”

Neal: “The acoustics in the room aren’t helpful at all. Even when there’s just the instructor speaking, because of the echo, I find that very difficult to cope with....yes the sound in the hall. Acoustics.”

It is interesting to note that Seema stopped coming to the weekly sessions soon after the mid-intervention focus group, and Neal’s self-reported depression scores worsened over time over the course of the 6 months.

3. The Learning Process:

Participants reflected on dimension of learning and the familiarisation of practice throughout the six months.

(second focus group):

Raymond: “It’s got much easier. That’s probably because I’ve learnt how to do it.”

Mark: “yeah it’s starting to sink in.”

Bill: “it’s quite a long and complicated form we do now and it’s taken me quite a long time to get into it as far as I have,

but I still find some bits I'm not very good at, but with time hopefully it will...I'll improve. But it is quite a complicated complex subject ermm...thing to do. It takes me a long time these days to get into it and master it."

The role and requirements of memory in participation and sense of progression in the group was debated.

Mark: "I found it quite good that there wasn't too much pressure to remember stuff like it was just the usefulness of doing the exercise in itself rather than having to learn... normally do I feel that I'd be letting the teacher down if I didn't. Yeh here it doesn't matter, sort of what you remember or not."

Bill: "I was a bit concerned of to start with was trying to remember all the moves in the form, but I know Alison kept on saying we don't need to remember it at all.... I felt I needed to have a lot of it in my memory to be able to carry out the sequence, but really it does just flow now. When I do join in with the form now, it does just come back quite quickly, although there are still bits that I do forget readily."

Participants spontaneously referred to the idea of flow, for moments in the session free of the aforementioned barriers:

Roger: "I think it has improved. I think I've got more into the flow of things."

Elements within the classes that supported this state of mind included moments when participants were following the TJ instructor, becoming absorbed in the present moment:

(first focus group):

Seema: "I don't think as such my tai chi practice has improved but I think I find it easier to do the form – not because ive remembered any of it in my head. I still don't. But I found it easier to follow the teacher and just automatically do, know what's coming next."

(second focus group)

Mark: "main thing for me is to be able to follow Alison (instructor)"

Participants differed in their attempts to practice the TJ movements at home, in between the classes. Memory difficulties and strategies to manage these were key determinants:

(first focus group)

Neal: "I still try every week to replicate what we learn in the class."

Seema: "what stops me from doing it is I just can't seem to remember."

Andy: "I remember the moves, I ... every 2 days I" (Interviewer: practice at home?) "Yeah yeah."

Neal: "I try and practice every day if I can find the time, but what I do find helpful is the recording I did of Alison doing the form on my phone."

Mark: "No I don't" (slight laughter). (Interviewer: No ok and what stops you?). "It's memory I think because I don't even remember."

4. Travel to Classes:

The final dimension of influence were the journeys to and from the TJ classes. Hospital transport was provided to facilitate access to the classes for those who did not have their own form of transport. However hospital transport journeys were long, and pick-ups were inconvenient relative to the times of the classes themselves. This had an impact on fatigue for participants:

(first focus group):

Neal: "Transport is a big issue. If transport mucks up basically you've got anxiety even before you even got here."

Bill: "yeah transport."

(second focus group):

Mark: "what's challenging about the actual doing the day is, for me is, the fatigue...with the coming in on transport, ermm they get us here very early and so it makes the day quite long and I have to sleep sort of all afternoon after it."

These challenges withstanding, two members of the group who had previously attempted generic TJ classes in the community contrasted the value of the ABI TJ group:

Neal: "I attended a tai chi class mainstream and I didn't get on with it, because of the memory factor and the way the course had been put across. I thought of doing it through the Enrych Cambourne scheme would be more adapted delivery for people with brain injury."

Mark: "same reason as Neal really, I do a course in (town), but with my balance issues and I guess difficulties with the memory as well so I wanted to do something that was more

tailored to people with balance problems or mobility problems. So it's not so much standing on one leg."

SUMMARY & CONCLUSION

Results have been shared from a pilot of a weekly Tai Ji group for survivors of acquired brain injury. The sample size is small and there are significant limitations on the generalisations that can be made from this data. However, the diversity in types of ABI and combinations of physical, cognitive and emotional difficulties evident in this small sample is commensurate with other population of acquired brain injury survivors using community resources (including healthcare resources, where available) on a long-term basis following the post-acute phase of their injuries. Detailed case study accounts of the needs and progress made by Raymond, Andy and Mark during the group are provided by Yeates (2019 a,b,c).

The findings from this study cannot be generalised, given the small sample. The tentative findings from this data that survivors responded differently to a TJ group intervention that was adapted only minimally for gross physical differences (standing versus seated practice), requires further elaboration and clarification in large sample studies. This diversity of response on standardised quantitative self-report measures included those who benefited in some domains, those that exhibited no clear benefit and 2 participants who demonstrated a negative trend (a reduction in mood) during the course of the six months). A third of participants left the group prematurely. Retention rates and contrasts of participants' response trajectories in future larger sample studies would be illuminative, rather than solely aggregated data.

The qualitative focus group data highlighted how participants experienced both common gains (relaxation alongside energy and enhanced social cohesion), but beyond the shared perceived challenge of memory during the classes, there was significant diversity across participants in identified challenges (physical, cognitive and emotional, environmental). The experience of the learning process was key to the location of gains versus challenges, and travel/transport to and from classes was identified as a key influence on the in-class and post-class experience.

When comparing both qualitative and quantitative data across participants, the majority consensus in the focus group of increased energy across those participants who completed the 6 month course was supported to a certain extent by common reductions in physical fatigue on the Modified Fatigue Impact Scale (Fisk et al., 1994) for those

participants over the six months. The co-existence of tiredness and revitalisation was noted by one participant. These trends are consistent with findings across large sample studies demonstrating a replicated finding of mind-body interventions such as TJ, yoga and mindfulness meditation being associated with significant benefits in fatigue and/or sleep disturbance for people with neurological conditions (e.g., Cramer et al., 2014; Grosman et al., 2010; Johansson et al., 2012; Lyu et al., 2018; Yeates et al., 2015). Fatigue was not the primary outcome in many of these studies however and as such future well-designed mind-body intervention studies are required that target this domain of post-injury functioning in particular.

Increased social cohesion was also a commonly identified gain by participants in the focus groups. No ABI TJ group studies to date have operationalised social cohesion/group membership as a core outcome. Given both the prioritisation of this dimension for post-injury identity reconstruction and psychological wellbeing (Haslam et al., 2008) and the prioritisation of this aspect by the focus-group responses from participants in this study, social group membership and its relationship to wellbeing should be a target for future TJ studies.

Two participants who uniquely identified significant challenges from the physical learning environment demonstrated negative quantitative outcomes (an increase in depression scores for Neal, and a premature leaving of the group sessions for Seema, who also did not demonstrate any improvement on any measure over the duration of the study). The offering of mind-body interventions within community and healthcare settings, either face-face or remotely, needs to be planned with the learning environment in mind for future intervention projects, and the role of the learning environment needs to be considered when interpreting results of mind-body evaluations in future research studies.

The diversity of participant responses and experienced benefits versus challenges to a standardised 6 month weekly TJ group with minimal adaptations to learning and practice supports the call for bespoke adaptation to be central to future TJ initiatives for ABI survivors. Yeates (2015; 2018; 2019 a,b,c) has provided a range of suggestions of how adaptations can be made to the learning and practice of TJ for different physical, cognitive, and psychological needs for each survivor within a group class format. Furthermore, the principle of optimising Flow State Experience (Csikszentmihalyi, 1997) is offered as a

conceptual framework to guide this adaptation process for each survivor. Future well-designed studies are recommended to investigate the physical, psychological and social gains of this new approach to TJ learning and practice for survivors of ABI. Comparisons of 1:1 versus group delivery formats are welcome in future studies, as are differing models for optimising bespoke adaptation within group formats.

Finally, while these adaptations have been conceptualised for the delivery of face to face TJ classes, the social distancing requirements in the current post-COVID 19 context require alternatives to shared physical space for TJ and other community interventions. At the same time, enduring post-viral difficulties in fatigue, pain, cognition, and mental health for COVID 19 patients (Rogers et al., 2020) and the evidence of ABI as a post-COVID 19 outcome itself make this new population (likely to overlap with survivors from non-COVID 19 related ABI) a relevant group for the potential benefits of TJ. Therefore, the evolution of adapted TJ within the literature will need to include remote modes of delivery to survivors in their homes. This virtual delivery of adapted TJ offers both a solution to the negative influences of travel to a TJ class, but suffers from different access issues for people with disabilities and offers fewer opportunities for social cohesion.

REFERENCES:

- Blake, H., & M. Batson. 2006. Exercise intervention in brain injury: a pilot randomized study of Tai Chi Qigong. *Clinical Rehabilitation* 23, 589–98.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Burschka, J. M., P. M. Keune, U. Oy, P. Oschman and P. Kuhn. 2014. Mindfulness-based interventions in multiple sclerosis: beneficial effects of Tai Chi on balance, coordination, fatigue and depression. *BioMedCentral Neurology* 14, 165–174.
- Charmaz, K. (1990). ``Discovering'' chronic illness: Using grounded theory. *Social Science & Medicine*, 30, 1161-1172.
- Cramer, H., R. Lauche, H. Azizi, G. Dobos & J. Langhorst. 2014. Yoga for multiple sclerosis: a systematic review and meta analysis. *PLoS One* 9, e112414.
- Csikszentmihalyi, M. 1990. *Flow: The Psychology of Optimal Experience*. New York: Harper and Row.
- Csikszentmihalyi, M. 1997. *Finding Flow: The Psychology of Engagement with Everyday Life*. New York: Basic Books.
- Department of Health. (2005). *The National Service Framework for Long-term Conditions*. Retrieved from the World Wide Web http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361
- Fisk, J. D., P. G. Ritvo, L. Ross, D. A. Haasem, T. J. Marrie & W. F. Schlech. 1994. Measuring the functional impact of fatigue: initial validation of the fatigue impact scale. *Clinical Infectious Disease* 18(Suppl. 1), s79–83.
- Gemmell, C., & J. M. Leathem. 2006. A study investigating the effects of Tai Chi Chuan: individuals with traumatic brain injury compared to controls. *Brain Injury* 2, 151–6.
- Grossman, P., Kappos, L., Gensicke, H., D'Souza, M., Mohr, D. C., Penner, I. K., & Steiner, C. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: a randomized trial. *Neurology*, 75(13), 1141-1149.

- Haslam, C., A. Holme, S. A. Haslam, A. Lyer, J. Jetten & W. H. Williams. 2008. Maintaining group memberships: social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation* 1, 671–91.
- Hung S-H, Hwang C-Y, Chang C-Y (2021) Is the Qi experience related to the flow experience? Practicing qigong in urban green spaces. *PLoS ONE* 16(1), e0240180. <https://doi.org/10.1371/journal.pone.0240180>
- Hwang, I., R. Song, S. Ahn, M. Lee, P. Wayne & M. K. Sohn. 2017. Exploring the adaptability of Tai Chi to stroke rehabilitation. *Rehabilitation Nursing*. Published online. doi:10.1097/rnj.0000000000000110.
- Jacobson, N. S. & P. Truax. 1991. Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology* 59, 12–19.
- Johansson, B., H. Bjhur & L. Rönnbäck. 2012. Mindfulness-based stress reduction (MBSR) improves long-term mental fatigue after stroke and traumatic brain injury. *Brain Injury* 26, 1621–8.
- Luria, A. R. 1975. *The Man with a Shattered World*. Harmondsworth, UK: Penguin Books.
- Lyu, D., X. Lyu, Y. Zhang, Y. Ren, F. Yang, L. Zhou, Y. Zou & Z. Li. 2018. Tai Chi for stroke rehabilitation: a systematic review and meta-analysis of randomized controlled trials. *Frontiers in Physiology* 9, 983. doi:10.3389/fphys.2018.00983.
- Nochi, M. 1997. Dealing with the 'void': traumatic brain injury as a story. *Disability & Society* 12, 533–55.
- Paterson, B., & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research*, 12(3), 399 – 409.
- Rogers, J. P., Chesney, E., Oliver, D., Pollak, T. A., Mcguire, P., Fusarpoli, P., ... Lewis, G. (2020). Psychiatric and neuropsychiatric presentations associated with severe coronavirus infections: a systematic review and meta-analysis with comparison to the COVID-19 pandemic. *The Lancet Psychiatry*, 1–17. [https://doi.org/10.1016/S2215-0366\(20\)30203-0](https://doi.org/10.1016/S2215-0366(20)30203-0)
- Taylor-Piliae, R.E. & Coull, B.M. (2012). Community-based Yang-style Tai Chi is safe and feasible in chronic stroke: a pilot study. *Clinical Rehabilitation*, 26(2), 121–131
- Taylor-Piliae, R. E., T. M. Hoke, J. T. Hepworth, L. D. Latt, B. Najafi et al. 2014. Effect of Tai Chi on physical function, fall rates and quality of life among older stroke survivors. *Archives of Physical Medicine and Rehabilitation* 9, : 816–24.
- Tyerman, A. (1999). Outcome measurement in a community head injury service. *Neuropsychological Rehabilitation*, 9, 481–491.
- Von Steinbüchel, N., L. Wilson, H. Gibbons, G. Hawthorne, S. Höfer, S. Schmidt, J. Truelle et al. 2010. Quality of Life after Brain Injury (QOLIBRI): scale development and metric properties. *Journal of Neurotrauma* 27: 1167–85.
- Winsler, S.J., Kannan, P., Pang, M., Smith, C. & Tsang, W.W. (2018). Potential Benefits and Safety of T'ai Chi for Balance and Functional Independence in People with Cerebellar Ataxia. *The Journal of Alternative & Complimentary Medicine*, 24(12), 1221–1223.
- Yeates, G.N. (2015). Flow State Experiences as a Biopsychosocial Guide for Tai Ji Intervention and Research in Neuro-Rehabilitation. *Neuro-Disability & Psychotherapy*, 3(1): 22–41.
- Yeates, G.N. (2019a). Eastern Spirituality, Mind-Body Practices and Neuro-rehabilitation. In A. Coles & J. Collicutt (eds). *The Neurology of Religion*. Cambridge, UK: Cambridge University Press, pp.191–213.
- Yeates, G.N. (2019b). Mind-body interventions for neurological conditions. In: G.N. Yeates & F. Ashworth. *Psychological Therapies in Neuropsychological Rehabilitation*. Hove: Psychology Press.
- Yeates, G.N. (2019c). The Potential Contribution of Mind-Body Interventions within Psychological Support following Aphasia: A conceptual review and case study. In K. Meredith & G.N. Yeates. (eds). *Neuro-Disability & Psychotherapy, Specialist Topics (vol II)*. *Psychotherapy & Aphasia: Supporting Emotions & Relationships*. Oxford: Routledge.
- Yeates, G. N., M. Murphy, J. Baldwin, J. Wilkes & M. Mahadevan. 2015. A pilot evaluation of a yoga group

for survivors of acquired brain injury in a community setting. *Clinical Psychology Forum* 267, 46–51.

Zheng, G., W. Zhou, R. Xia, J. Tao & L. Chen. 2016. Aerobic exercises for cognition rehabilitation following stroke: a systematic review. *Journal of Stroke and Cerebrovascular Disease* 25, 2780–9

Zigmond, A. S. & R. P. Snaith. 1983. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 67, 361–70z

DESARROLLO Y VALIDEZ DE UN NUEVO TEST DE FUNCIONES EJECUTIVAS LIBRE DE SESGO POR ESCOLARIDAD (TELE).

DEVELOPMENT AND VALIDITY OF A NEW TEST OF EXECUTIVE FUNCTIONS FREE OF SCHOOLING BIAS (TELE).

MIGUEL RAMOS-HENDERSON*¹, ANDRÉS LEDEZMA-DAMES¹, CAMILA DEVIA-HENRIQUEZ¹, DANIELA HERNANDEZ-GALLARDO¹

* Correspondencia:

Miguel Ramos-Henderson
miguelramoshe@santotomas.cl

No existen instrumentos de evaluación cognitiva libres de sesgo educacional, para pesquisar funciones ejecutivas en personas mayores (PM) con bajo nivel educativo. Frente a esto, el objetivo del presente estudio fue determinar la validez de un nuevo test para evaluar las funciones ejecutivas (TELE) de PM, libre de sesgo por escolaridad. Para esto, se llevó a cabo un estudio no experimental, transversal e instrumental, en una muestra compuesta por un total de 90 participantes, de nacionalidad chilena, de los cuales, 74 fueron personas mayores cognitivamente sanas (grupo control) y 16 con diagnóstico de trastorno neurocognitivo mayor leve (TNCM). Se utilizó el Addenbrook's Cognitive Assessment III (ACE III) y el Trail Making Tests (TMT) parte A y B, como pruebas cognitivas de comparación y la escala Activities of Daily Living Questionnaire (T-ADLQ) para evaluar el deterioro funcional. Posteriormente, un evaluador ciego a los resultados de estas pruebas y al diagnóstico de los participantes, aplicó el TELE. Se establecieron tres grupos de comparación, control cognitivamente sano de baja escolaridad (2 a 8 años), escolaridad media (9 a 12 años) y un grupo clínico con diagnóstico de TNCM. Utilizando la prueba ANOVA con post hoc de Tukey, se encontró que a diferencia de TMT y ACE III, TELE total y TELE tiempo, no presentó diferencias significativas entre los grupos controles de distinto nivel de escolaridad, pero sí con el grupo TNCM. TELE tiempo y total, mostraron correlación positiva de nivel moderado a alto con TMT y ACE III, y correlación negativa con T-ADLQ. De todos los test cognitivos aplicados, solo TELE no fue afectado por los años de escolaridad, según lo reportado por el análisis de covarianza ANCOVA (TELE total: $p=.570$, TELE tiempo: $p=.273$). Conclusión: TELE es un test para evaluar FE, capaz de diferenciar PM cognitivamente sanas, de personas mayores con trastorno neurocognitivo mayor leve, cuenta con validez convergente y no se encuentra afectado por los años de escolaridad.

Palabras claves: Test cognitivo, Personas mayores, Bajo nivel educativo, Funciones ejecutivas, Demencia.

There are no cognitive assessment instruments free of educational bias to investigate executive functions in older adults (EI) with low educational level. In view of this, the aim of the present study was to determine the validity of a new test to assess executive functions (TELE) in the elderly, free of educational bias. For this purpose, a non-experimental, cross-sectional and instrumental study was carried out in a sample composed of a total of 90 participants, of Chilean nationality, of which 74 were cognitively healthy elderly people (control group) and 16 with a diagnosis of mild major neurocognitive disorder (MND). The Addenbrook's Cognitive Assessment III (ACE III) and the Trail Making Tests (TMT) part A and B were used as cognitive comparison tests and the Activities of Daily Living Questionnaire (T-ADLQ) scale to assess functional impairment. Subsequently, an evaluator blinded to the results of these tests and to the participants' diagnosis, applied the TELE. Three comparison groups were established, cognitively healthy control with low schooling (2 to 8 years), middle schooling (9 to 12 years) and a clinical group with a diagnosis of NCCD. Using the ANOVA test with Tukey's post hoc, it was found that, unlike TMT and ACE III, TELE total and TELE time did not show significant differences between the control groups with different levels of schooling, but did show significant differences with the TNCM group. TELE time and total showed a moderate to high positive correlation with TMT and ACE III, and a negative correlation with T-ADLQ. Of all the cognitive tests applied, only TELE was not affected by years of schooling, as reported by the ANCOVA analysis of covariance (TELE total: $p=.570$, TELE time: $p=.273$). Conclusion: TELE is a test to assess EF, able to differentiate cognitively healthy PM from older people with mild major neurocognitive disorder, has convergent validity and is not affected by years of schooling.

Key words: Cognitive test, Elderly, Low educational level, Executive functions, Dementia.

¹ Centro de Investigación e Innovación en Gerontología Aplicada CIGAP, Facultad de Salud, Universidad Santo Tomás, Antofagasta, Chile.

INTRODUCCIÓN

Las funciones ejecutivas (FE) son procesos cognitivos de alto nivel que incluyen iniciación, planificación, flexibilidad, supervisión e inhibición de conductas (Diamond, 2013). Si bien existen ciertas discrepancias en cuanto a su definición (Ardila, 2018; Goldstein et al., 2014), se sabe que los cambios estructurales y funcionales a nivel prefrontal durante el envejecimiento (Gunning-Dixon y Raz, 2003; Maillet y Rajah, 2013) se asocian a un declive de las FE, afectando procesos como la memoria de trabajo, planificación, flexibilidad cognitiva e inhibición (Ferguson et al., 2021). Las FE, pueden manifestar alteraciones en presencia de diversas patologías psiquiátricas y neurológicas. Por ejemplo, en personas mayores depresivas, existe una disfunción fronto-estriatal que provoca manifestaciones de un síndrome disejecutivo (Alexopoulos et al., 2005; Monteiro et al., 2016; Pantzar et al., 2014). En estos pacientes, una mayor alteración de las FE, puede aumentar el deterioro funcional (Ramos-Henderson et al., 2021) o por el contrario, predecir respuesta favorable al tratamiento, en caso de contar con FE en mejor estado (Morimoto et al., 2016).

Por otro lado, la fuerte relación entre alteraciones disejecutivas y pérdida de la funcionalidad en personas mayores (Lahav y Katz, 2020; Marshall et al., 2011), le otorga al deterioro de las FE, un valor predictivo para anticipar la transición desde el deterioro cognitivo leve a la demencia (García-García-Patino et al., 2020; Junquera et al., 2020; Putcha y Tremont, 2016). En esta línea, además de las manifestaciones conductuales y disejecutivas características de las demencias frontotemporales (Moheb et al., 2017; Tartaglia et al., 2012), también se han descrito alteración de las FE en la enfermedad de Alzheimer (Fogarty et al., 2017; Guarino et al., 2019), Parkinson (Dirnberger y Jahanshahi, 2013), enfermedad por cuerpos de Lewy (Firbank et al., 2016) y demencias vasculares (Sudo et al., 2017), manifestándose incluso en fases prodrómicas de estas (Blanco Martín et al., 2016; Clark et al., 2012).

Desde este marco, resulta fundamental contar con pruebas que permitan evaluar las FE de forma adecuada y oportuna. En esta línea, una completa revisión sistemática (Faria et al., 2015), determinó que las pruebas más utilizadas para evaluar FE en personas mayores son: el Trail Making Test parte B (TMT B), Test de fluencia fonológica (FAS), test de Stroop y el Test del reloj (TR). Salvo este último, todos los test mencionados, poseen normalizaciones chilenas, ajustadas por edad y nivel educativo (Arango-Lasprilla et

al., 2015; Olabarrieta-Landa et al., 2015; Rivera et al., 2015). Específicamente, para el tamizaje de las FE, solo se cuenta con el Frontal Assessment Battery (FAB) (Dubois et al., 2000; Grandi et al., 2022), el INECO Frontal Screening (IFS) (Ihnen et al., 2013) y el Montreal Cognitive Assessment (MoCA). Este último, a pesar de ser un test de eficiencia cognitiva global, posee un énfasis en las FE (Nasreddine et al., 2005).

A pesar de la existencia de estas pruebas, un par de revisiones sistemáticas (Pellicer-Espinosa y Díaz-Orueta, 2021; Tavares-Júnior et al., 2019), analizaron de forma crítica los test cognitivos breves para personas mayores de bajo nivel educativo. Estas revisiones, reportaron que existen escasos estudios de validación para sujetos con menos de 4 años de educación. A su vez, se encontró elevado sesgo por nivel educativo en los test que involucran lectura, escritura, cálculo, dibujos, praxias y visoconstrucción (Pellicer-Espinosa y Díaz-Orueta, 2021). Otra revisión sistemática (Custodio et al., 2020), se enfocó en la utilidad diagnóstica de test cognitivos breves en Latinoamérica, encontrando que los participantes evaluados tenían en promedio 10 años de educación. Solo uno de los estudios revisados, contaba con personas mayores con menos de 5 años de escolarización, en quienes solo se evaluó el proceso de memoria episódica (Custodio et al., 2017). A su vez, si bien el MoCA es uno de los test más utilizados en la región, este se encuentra significativamente influenciado por el nivel educativo, ocurriendo lo mismo con los test abocados a la función ejecutiva como el caso del IFS (Custodio et al., 2020).

Esto es importante, considerando que los datos de 146 países indican que el 14% de las personas en el mundo, no reciben ningún tipo de educación formal y que un 40% solo asistieron a la escuela primaria (Barro y Lee, 2013). En Chile, 49,4% de las personas mayores no completo su enseñanza básica (CASEN, 2017). Así mismo, el bajo nivel educativo se ha reportado como un determinante de sub-diagnóstico de demencia (Savva y Arthur, 2015), el cual se estima en un 61,7% a nivel mundial (Lang et al., 2017).

La mayoría de las pruebas cognitivas utilizadas, requieren de lectura, escritura o uso de lápiz y papel (Paddick et al., 2017). Por ejemplo el test más utilizado para evaluar FE en personas mayores es el TMT B (Faria et al., 2015), sin embargo, requiere un conocimiento perfecto del orden alfabético (Kim et al., 2014). En otro test muy utilizado, el FAS, se ha reportado que los años de escolaridad explican casi el 30% de la varianza en su rendimiento (Olabarrieta-Landa et al., 2015; Zimmermann et al., 2014). En el caso del TR, se

requiere lápiz, papel y habilidad visuoconstructiva, siendo este último un aspecto muy sensible al sesgo por nivel educativo (Kim y Chey, 2010; Lourenço et al., 2008)

Existen otras pruebas para evaluar las FE basadas en el paradigma Stroop (Scarpina y Tagini, 2017; Stroop, 1935). El aspecto central de estas, radica en el retraso en el tiempo de reacción ante el procesamiento automático, para lo cual, es necesario un tipo de control ejecutivo denominado "inhibición" (Persad et al., 2002). Para esto, es importante la capacidad resistir la tendencia a emitir la respuesta automática y mantener activamente las metas a realizar (Kane y Engle, 2003; Morey et al., 2012). Esta capacidad muestra un claro correlato con activación de regiones prefrontales y corteza cingulada del cerebro (Song y Hakoda, 2015; Yun et al., 2011). Sin embargo, el test de Stroop (Stroop, 1935) basado en el paradigma, tiene como principal limitación la necesidad de contar con capacidad lectora (Protopapas et al., 2007). Por otro lado, se ha reportado que el uso de colores y el tamaño de los estímulos pueden desde el punto de vista visual, interferir con su aplicación y resultados (van Boxtel et al., 2001). Igualmente, se ha reportado que algunas personas utilizan estrategias para disminuir el efecto Stroop, enturbiando la vista mientras desvían los ojos de los estímulos presentados al centro (Irwin, 1978; Raz et al., 2003). Por el contrario, en personas mayores con niveles educativos más altos, las tareas basadas en paradigma Stroop, han demostrado ser más útiles que otras pruebas de FE, para discriminar personas mayores cognitivamente sanas, de quienes presentan enfermedades neurodegenerativas en fases tempranas del deterioro cognitivo (Guarino et al., 2019; Hutchison et al., 2010).

En virtud de los escasos de pruebas de FE diseñadas para personas mayores de bajo nivel educativo, el objetivo general del presente estudio es, determinar la validez de un nuevo test para evaluar las funciones ejecutivas (TELE) de personas mayores, libre de sesgo por escolaridad. Para la consecución del objetivo general, los objetivos específicos son: 1) Determinar las características sociodemográficas, desempeño cognitivo y deterioro funcional de los participantes. 2) Analizar el nivel de validez discriminante y convergente del TELE. 3) Evaluar la influencia de variables sociodemográficas (edad y escolaridad) en el desempeño del TELE.

En congruencia con los objetivos, las hipótesis del estudio son: 1) No existirán diferencias significativas en el desempeño de TELE entre personas mayores de bajo y alto nivel educativo, 2) Existirán diferencias significativas en el desempeño de TELE, entre los participantes del grupo

control sin deterioro cognitivo y aquellos que pertenecen al grupo clínico, 3) TELE obtendrá correlación significativa y positiva con el resto de los test cognitivos, y a su vez, correlación significativa y negativa con deterioro funcional, 4) Los análisis de covarianza (ANCOVA), revelarán que la edad y los años de escolaridad no influyen en el desempeño del TELE.

MATERIALES Y MÉTODO

Diseño y Participantes

El presente es un estudio no experimental, transversal e instrumental, llevado a cabo en una muestra compuesta por un total de 90 participantes, de nacionalidad chilena, de los cuales, 74 fueron personas mayores cognitivamente sanas (grupo control) y 16 con diagnóstico de trastorno neurocognitivo mayor leve. En el caso del grupo control, estos fueron convocados desde la comunidad y debían cumplir con los criterios de inclusión: a) tener 55 o más años; b) escolaridad inferior a 13 años. c) no presentar deterioro funcional significativo confirmado con un puntaje < 29 pts en la escala Activities of daily living questionnaire (T-ADLQ) (Muñoz-Neira et al., 2012); d) ausencia de deterioro cognitivo compatible con demencia expresado en un puntaje >66 en el Addensbrooke's Cognitive Examination III (ACE III) (Véliz García et al., 2020). Fueron excluidos del grupo control sujetos con diagnóstico de depresión, trastorno de ansiedad, consumo de drogas o que hayan tenido enfermedades neurológicas como accidente cerebrovascular y/o demencia. Igualmente, quienes presentaban déficit sensorial como hipoacusia severa o pérdida de visión, quedaban excluidos del estudio. El reclutamiento se llevó a cabo desde centros comunitarios, juntas de vecinos y casas recreacionales para personas mayores de la ciudad de Antofagasta. El estudio fue aprobado por el Comité de Ética de Universidad Santo Tomás y todos los participantes firmaron un consentimiento informado por escrito.

La muestra clínica se obtuvo desde la Unidad de Neuropsicología Clínica de Universidad Santo Tomás, sede Antofagasta, asociada al Centro de Investigación e Innovación en Gerontología Aplicada CIGAP. A esta unidad, son derivadas personas mayores desde el Servicio de Neurología del Hospital Regional de Antofagasta con sospecha de demencia. El diagnóstico de trastorno neurocognitivo mayor leve (TNLM) fue realizado por médico neurólogo basado en los criterios DSM V y por evaluación neuropsicológica para confirmar deterioro cognitivo y funcional.

INSTRUMENTOS

Test de funciones ejecutivas libre de sesgo por escolaridad (TELE).

El TELE, consisten en una tarea en donde el evaluado se enfrenta a una serie de cinco filas de entre catorce a quince puntos negros de tamaño chico y grande, distribuido a lo largo de una hoja horizontal (figura 1). En el menor tiempo posible, el evaluado debe tocar en orden de izquierda a derecha, cada uno de los puntos y verbalizar el tamaño contrario. Es decir, si toca un punto grande debe decir "chico" y si toca un punto chico debe decir "grande". Para evitar que se "salte" alguno de los puntos, se le pide que los vaya tocando mientras verbaliza la respuesta. A su vez, esto facilita el conteo de errores por parte del evaluador.

La tarea, tiene como componente central el control inhibitorio (Diamond, 2013), dado que se debe evitar una respuesta automática previamente aprendida (tamaño de los círculos), por una respuesta alternativa (tamaño contrario), emulando los principios del paradigma Stroop (Scarpina y Tagini, 2017; Stroop, 1935). Adicionalmente, se requiere energización para iniciar la conducta dirigida al propósito (Henri-Bhargava et al., 2018), y atención sostenida para mantenerse de forma estable hasta el final de la tarea, similar a lo requerido en el TMT parte A (Arango-Lasprilla et al., 2015). Por otro lado, mantener la consigna respecto del propósito, para dirigir la conducta al objetivo señalado, sugieren que la memoria de trabajo verbal (Chai et al., 2018), tendría igualmente un rol en la ejecución del TELE. Finalmente, la consideración del tiempo empleado en su ejecución, entrega una medida adicional e independiente, de velocidad de procesamiento cognitivo (Ebaid et al., 2017).

Antes de iniciar la tarea, existe un ítem de ejemplo, en donde se explica el procedimiento y se practica hasta que el evaluado logre seguir la instrucción. La prueba inicia con un máximo de 12 puntos (TELE total), y se va descontando un punto por cada error cometido, sin detener al evaluado frente a los errores. En paralelo, se toma el tiempo que demora en tocar todos los puntos (TELE tiempo). Si el evaluado comete 12 errores, obtiene 0 pts. en TELE total. Siguiendo el criterio de corrección del TMT B (Arango-Lasprilla et al., 2015) se le asignan 300 segundos en TELE tiempo, si no puede finalizar la tarea, o si obtiene 0 pts. en TELE total. Su aplicación completa, toma en promedio 2 minutos.

El anexo descrito en la figura 1 y su protocolo de aplicación, puede encontrarse en el material suplementario del presente artículo (Apéndice 1).

Ejemplo

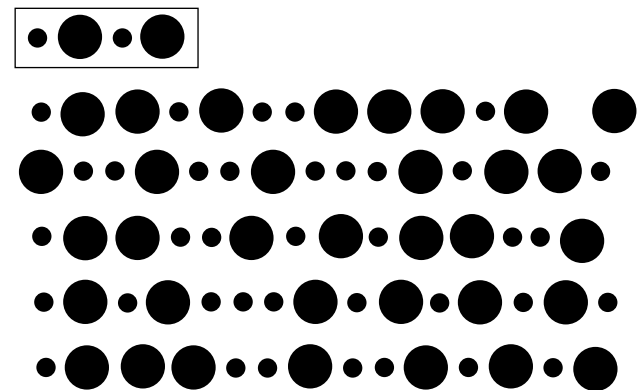


Figura 1. Anexo de aplicación TELE.

El TELE fue sometido a una fase de validación por criterio de expertos. Para esto, se diseñó un formulario Google form, el cuál contenía el test y una definición conceptual y operacional de control inhibitorio como faceta de las FE. A su vez, el formulario contenía las instrucciones de aplicación y los criterios de corrección de puntajes y un espacio para comentarios u observaciones. Se realizaron cuatro preguntas específicas con respuesta dicotómica (Si/No): ¿El test permite evaluar funciones ejecutivas?, ¿El test permite evaluar control inhibitorio?, ¿Las instrucciones están redactadas de forma clara?, ¿Considera que la puntuación es apropiada para el test?. Este formulario se envió a cinco expertos con formación de post grado en neuropsicología y experiencia de al menos tres años en el campo de la neuropsicología clínica con personas mayores. Todos los expertos coincidieron en que el TELE permite medir funciones ejecutivas, control inhibitorio y que sus instrucciones y sistema de puntuación resultan apropiados.

Otros test cognitivos.

Para la evaluación de la eficiencia cognitiva global, se aplicó la versión chilena del ACE III, el cuál es una prueba cognitiva heteroaplicada, que se compone de 81 ítems distribuidos en cinco sub-escalas: atención, memoria, fluencias verbales, lenguaje y habilidades visoespaciales. Tiene un puntaje máximo de 100 pts y presenta una adecuada fiabilidad ($\alpha = 0,87$) (Bruno et al., 2020). Un estudio más reciente, determinó un puntaje de corte de 66 pts para identificar demencia con una sensibilidad de 0.97 y especificidad de 0.81 en personas de la ciudad de Antofagasta (Véliz García et al., 2020).

La evaluación de FE con prueba cognitiva “estándar de oro”, se realizó con el TMT versión chilena (Arango-Lasprilla et al., 2015). Esta se divide en una parte A, que consiste en unir con una línea, 25 números en orden, distribuidos en una hoja, y una parte B, que consisten en unir en orden alternante, números y letras (1-A-2-B...). La primera parte permite evaluar atención, búsqueda visual y velocidad psicomotriz, mientras que la segunda, evalúa flexibilidad cognitiva y control ejecutivo.

Valoración funcional.

Para la valoración funcional se utilizó el T-ADLQ (Muñoz-Neira et al., 2012), el cual se aplicó a un familiar de cada participante. Esta escala considera el punto de vista de un familiar quien debe evaluar seis dominios de actividades básicas, instrumentales y avanzadas de la vida diaria. Con una puntuación >29 pts., presenta una sensibilidad y especificidad de 0.81 y 0.90, para detectar deterioro funcional compatible con demencia.

Procedimiento

Posterior a la fase de validación de expertos, todos los participantes reclutados fueron evaluados por psicólogos entrenados en aplicación de pruebas cognitivas, con la versión chilena del ACE III, TMT y T-ADLQ. Finalmente, un segundo psicólogo entrenado, ciego a los diagnósticos y resultados de los test cognitivos y funcionales, aplicó el TELE a los participantes. Todas las evaluaciones, fueron realizadas entre junio de 2018 a enero de 2019.

Análisis estadísticos

Todos los análisis se realizaron con el paquete estadístico SPSS 25 para Windows. Se establecieron tres grupos de comparación, controles cognitivamente sanos de baja escolaridad (2 a 8 años), escolaridad media (9 a 12 años) y grupo clínico (TNCM).

El análisis de datos sociodemográficos y la comparación de test cognitivos entre los grupos para determinar validez discriminante, se realizó con la prueba ANOVA y post hoc de Tukey. Para obtener evidencia de validez convergente, basada en asociación positiva entre TELE total y el resto de las pruebas cognitivas (ACE III, TMT A y B), y asociación negativa con deterioro funcional (T-ADLQ), se utilizó correlación de Pearson.

Finalmente, para determinar la influencia y tamaño del efecto de la edad, escolaridad y diagnóstico, sobre

las pruebas cognitivas, se utilizó un análisis de covarianza ANCOVA y eta al cuadrado respectivamente. Para todas las pruebas estadísticas, se utilizó un nivel de significancia mínima de $p < 0.05$.

RESULTADOS

Variabes sociodemográficas y rendimiento cognitivo.

La muestra total, presentó un rango de edad que va de los 55 a los 91 años, con una media de 69.94 y una desviación estándar de 8.54. Por su parte, la escolaridad presentó una media total de 8.62 años con una desviación estándar de 3.03. No se observaron diferencias significativas en la distribución por sexo entre los grupos. Considerando los grupos de control, la media en TELE total fue de 9.55 con una desviación estándar de 1.80. En el caso de TELE tiempo, la media fue 85.09 y una desviación estándar de 45.03. En relación con la edad, el grupo TCNM es significativamente mayor que los grupos de control. En cuanto a la escolaridad, el grupo TCNM es homogéneo con el grupo control menos escolarizado ($p=0,904$). Respecto del desempeño en los test cognitivos, se observaron diferencias significativas entre los grupos de control y el grupo clínico, en los test ACE III y TMT B, siendo el grupo de control más escolarizado el de mejor desempeño. En ambos test, el grupo TCNM, presentó el rendimiento más bajo al compararse con los grupos de control. No se observó diferencias en el desempeño de TMT A, TELE total, TELE tiempo y T-ADLQ, entre los grupos de control, pero si con el grupo TNCM, el cuál presentó un menor desempeño en los test cognitivos y un mayor nivel de deterioro funcional (Tabla 1).

En congruencia con la hipótesis 1, se encontró que TELE no presentó diferencias significativas entre personas mayores cognitivamente sanas, de diferente nivel educativo.

Validez discriminante y convergente.

Se observaron diferencias significativas entre los grupos de control y el grupo TNCM en el rendimiento de TELE total y TELE tiempo (Tabla 1), obteniéndose un tamaño de efecto alto en ambos casos ($\eta^2=0.39$ y $\eta^2=0.11$, respectivamente). Esto confirma la validez discriminante del TELE. Respecto de la validez convergente (Tabla 2), TELE total y TELE tiempo, mostraron correlación significativa y moderada con el test de funciones ejecutivas estándar de oro (TMT B). Adicionalmente, se encontró correlación significativa con TMT A y con el nivel de eficiencia cognitiva global ACE III, evidenciando ausencia de validez divergente. Finalmente, se

encontró una correlación negativa y significativa entre el nivel de deterioro funcional (T-ADLQ), TELE total y TELE tiempo.

Influencia de variables sociodemográficas en el desempeño del TELE.

El análisis de covarianza (tabla 3), muestra que la edad no influyó en el desempeño de TELE total y TELE tiempo. Igualmente, a diferencia de ACE III, TMT A y TMT B, los años de escolaridad tampoco afectaron la varianza de TELE total ni TELE tiempo. Por el contrario, la mayor parte de la variabilidad de TELE total y tiempo, se debieron a la presencia de TCNM. Estos resultados confirman que TELE no está influenciado por variables sociodemográficas, pero sí por la presencia de deterioro cognitivo.

DISCUSIÓN

Con el propósito de entregar una herramienta sencilla para evaluar la FE de personas mayores, exenta de la influencia del nivel educativo, nos propusimos diseñar una nueva prueba breve, el TELE. Tal como esperábamos, al igual que las pruebas "estándar de oro", el TELE pudo diferenciar entre personas mayores cognitivamente sanas y con TCNM, confirmando validez discriminante. Igualmente, a partir de su buen nivel de correlación con otro test de funciones ejecutivas, confirmó validez convergente. Si bien, no se confirmó validez divergente del TELE, dado que correlacionó con test cognitivos que no miden directamente funciones ejecutivas, esto se ha observado previamente en todas las baterías diseñadas para evaluar este dominio (Dubois et al., 2000; Grandi et al., 2022; Ihnen et al., 2013). Esto, se puede explicar en el hecho de que los dominios cognitivos no son independientes entre sí, y el funcionamiento ejecutivo ejerce control sobre la utilización del resto de procesos cognitivos (Diamond, 2013; Harvey, 2019).

A diferencia del resto de las pruebas cognitivas utilizadas, el TELE no se vio afectado por los años de escolaridad de los participantes. En el caso del ACE III, existe evidencia consistente de que el nivel educativo interfiere de forma significativa en su desempeño (Bruno y Schurmann Vignaga, 2019; Nieto et al., 2016) afectando su utilidad clínica en sujetos poco escolarizados. Por su parte, el TMT A y B se vieron igualmente afectados por el nivel educativo de los participantes de nuestro estudio, siendo consistente con lo reportado previamente (Arango-Lasprilla et al., 2015; de Azeredo Passos et al., 2015). Esto, parece reafirmar la idea de que el uso de tareas que involucren cálculo, lectura y escritura, como en el caso del ACE

III, explican estas limitaciones (Paddick et al., 2017). Así mismo, el requerimiento de conocimiento alfabético y el uso de lápiz y papel, como es el caso del TMT A y B (Carnero-Pardo, 2014; Kim et al., 2014), parecieran explicar el sesgo educacional en estos test. En el caso del TELE, no se requiere de ninguna de estas capacidades asociadas a la escolarización, por lo cual, se vuelve apropiada para personas mayores de bajo nivel educativo que suelen tener dificultades en los test tradicionales (Tavares-Júnior et al., 2019).

Así mismo, hemos demostrado que conservando la esencia del paradigma Stroop, y retirando el uso de colores similares que pueden resultar confusos para personas con limitación visual (van Boxtel et al., 2001), así como la necesidad de utilizar lectura (Protopapas et al., 2007), ha sido posible contar con una prueba cognitiva breve, que rescate los beneficios de este paradigma y que además resulte inclusiva para personas poco escolarizadas, evitando el "sesgo educacional".

A pesar de estos resultados, el presente estudio no está exento de limitaciones. La primera, dice relación con el tamaño de la muestra y la ausencia de personas mayores analfabetas y de procedencia rural. Por otro lado, no se incluyó medidas de neuroimagen que corroboraran los correlatos de activación cerebral reportados en otros estudios (Song y Hakoda, 2015; Yun et al., 2011). Igualmente, la muestra clínica no especificó diagnósticos neurológicos como enfermedad de Alzheimer, Parkinson o Demencia fronto-temporal. Tampoco se incluyeron personas mayores con deterioro cognitivo leve, ni se utilizaron, además del TMT B, otras medidas cognitivas de FE, como el mismo test de Stroop original o el Frontal Assessment Battery, que ya cuenta con ajustes por nivel educativo (Grandi et al., 2022). En este sentido, futuras investigaciones deberán considerar muestras más extensas, personas analfabetas cognitivamente sanas y participantes que vivan entornos rurales. Igualmente, se debe probar la utilidad diagnóstica del TELE para diferencias distintos tipos de enfermedades neurodegenerativas que afecten las FE de forma primaria.

Teniendo en consideración estas limitaciones, nuestros resultados sugieren que el TELE, es un test para FE capaz de diferenciar personas mayores cognitivamente sanas de personas mayores con trastorno neurocognitivo mayor leve, cuenta con validez convergente y no se encuentra afectado por los años de escolaridad.

Esta nueva herramienta tiene múltiples implicancias en el ámbito clínico, siendo aplicable en contextos de atención primaria por su corta duración y sencillez. Así mismo,

Tabla 1. Aspectos sociodemográficos y rendimiento cognitivo de los grupos.

	Controles por educación		Clínico	F	p
	2 a 8 años	9 a 12 años	TNC Mayor		
	N= 35	N= 39	N= 16		
	M ± DE	M ± DE	M ± DE		
Edad	68.31 ± 7.62	67.41 ± 6.82	79.68 ± 7.70	17.48	.000**ac
Escolaridad	6.54 ± 1.52	11.43 ± 0.88	6.31 ± 3.34	86.05	.000**bd
TELE total	9.08 ± 1.81	9.97 ± 1.70	4.00 ± 4.36	35.87	.000**ac
TELE tiempo	100.91 ± 45.35	70.89 ± 40.22	190.31 ± 116.44	21.08	.000**ac
ACE III	80.47 ± 9.43	86.53 ± 6.13	57.13 ± 14.60	54,68	.000**abc
TMT A	54.20 ± 21.14	42.35 ± 17.69	128.75 ± 31.74	91.08	.000**ac
TMT B	142.25 ± 54.40	101.38 ± 52.09	278.06 ± 47.35	65.33	.000**abc
T-ADLQ	4.13 ± 6.39	5.10 ± 6.82	51.87 ± 17.30	166.9	.000**ac
	N (%)	N (%)	N (%)	X ²	P
Hombres	10 (28.57)	14 (35.89)	8 (50.00)	2.204	.332
Mujeres	25 (71.42)	25 (64.10)	8 (50.00)		

p<0.05*; p<0.01**; TELE: Test ejecutivo libre de escolaridad, ACE III: Addensbrook´s Cognitive Examination III, TMT: Trail Making test; T-ADLQ: Technology – Activities Daily Living Questionaire; TNC Mayor: Trastorno Neurocognitivo Mayor; a= 2 a 8 años < TNC Mayor; b= 2 a 8 años < 9 a 12 años; c= 9 a 12 años < TNC Mayor; d= TNC Mayor < 9 a 12 años

Tabla 2. Correlación Pearson de pruebas cognitivas

	ACE III	TMT A	TMT B	T-ADLQ	TELE tiempo
TELE total	.607**	-.586**	-.607**	-.537**	-.748**
TELE tiempo	-.436**	.517**	.648**	.450**	

p<0.05*; p<0.01**.

TELE: Test ejecutivo libre de escolaridad, ACE III: Addensbrook´s Cognitive Examination III, TMT: Trail Making test. T-ADLQ: Technology – Activities Daily Living Questionaire.

Tabla 3. ANCOVA: Efecto de la edad y escolaridad en las pruebas cognitivas

		F	p	n ²	α
Edad	TELE total	0.032	.858	.000	.054
	TELE tiempo	0.049	.826	.001	.055
	TMT A	6.013	.016*	.067	.679
	TMT B	8.280	.005*	.090	.812
	ACE III	1.559	.215	.018	.235
	T-ADLQ	0.527	.470	.006	.111
Escolaridad	TELE total	0.325	.570	.004	.087
	TELE tiempo	1.219	.273	.014	.194
	TMT A	5.364	.023*	.060	.629
	TMT B	8.116	.006*	.088	.804
	ACE III	5.053	.027*	.057	.603
	T-ADLQ	4.805	.031*	.054	.582
TNC Mayor	TELE total	48.968	.000**	.368	1.000
	TELE tiempo	26.641	.000**	.241	0.999
	TMT A	78.952	.000**	.285	1.000
	TMT B	45.221	.000**	.350	1.000
	ACE III	47.995	.000**	.364	1.000
	T-ADLQ	228.782	.000**	.731	1.000

p<0.05*; p<0.01**.

TELE: Test ejecutivo libre de escolaridad, ACE III: Addensbrook´s Cognitive Examination III, TMT: Trail Making test. T-ADLQ: Technology – Activities Daily Living Questionnaire. TNC Mayor: Trastorno Neurocognitivo Mayor.

puede utilizarse en contextos de investigación en donde se requiera evaluar funciones ejecutivas personas mayores con bajo educativo.

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CONFLICTO DE INTERES

Los autores del presente manuscrito declaran no presentar conflictos de interés.

REFERENCIAS

- Alexopoulos, G. S., Kiosses, D. N., Heo, M., Murphy, C. F., Shanmugham, B., & Gunning-Dixon, F. (2005). Executive dysfunction and the course of geriatric depression. *Biological Psychiatry*, *58*(3), 204–210. <https://doi.org/10.1016/j.biopsych.2005.04.024>
- Arango-Lasprilla, J. C., Rivera, D., Aguayo, A., Rodríguez, W., Garza, M. T., Saracho, C. P., Rodríguez-Agudelo, Y., Aliaga, A., Weiler, G., Luna, M., Longoni, M., Ocampo-Barba, N., Galarza-Del-Angel, J., Panyavin, I., Guerra, A., Esenarro, L., García de la Cadena, P., Martínez, C., & Perrin, P. B. (2015). Trail Making Test: Normative data for the Latin American Spanish speaking adult population. *NeuroRehabilitation*, *37*(4), 639–661. <https://doi.org/10.3233/NRE-151284>
- Ardila, A. (2018). Origins of Executive Functions. In A. Ardila (Ed.), *Historical Development of Human Cognition: A Cultural-Historical Neuropsychological Perspective* (pp. 107–134). Springer. https://doi.org/10.1007/978-981-10-6887-4_6
- Barro, R. J., & Lee, J. W. (2013). A new data set of educational attainment in the world, 1950–2010. *Journal of Development Economics*, *104*, 184–198. <https://doi.org/10.1016/j.jdeveco.2012.10.001>
- Blanco Martín, E., Ugarriza Serrano, I., Elcoroaristizabal Martín, X., Galdos Alcelay, L., Molano Salazar, A., Bereincua Gandarias, R., Inglés Borda, S., Uterga Valiente, J. M., Indakoetxea Juanbeltz, M. B., Moraza Lopez, J., Barandiarán Amillano, M., & Fernández-Martínez, M. (2016). Dysexecutive syndrome in amnesic mild cognitive impairment: A multicenter study. *BMC Neurology*, *16*, 88. <https://doi.org/10.1186/s12883-016-0607-2>
- Bruno, D., & Schurmann Vignaga, S. (2019). Addenbrooke's cognitive examination III in the diagnosis of dementia: A critical review. *Neuropsychiatric Disease and Treatment*, *15*, 441–447. <https://doi.org/10.2147/NDT.S151253>
- Bruno, D., Slachevsky, A., Fiorentino, N., Rueda, D. S., Bruno, G., Tagle, A. R., Olavarria, L., Flores, P., Lillo, P., Roca, M., & Torralva, T. (2020). Validación argentino-chilena de la versión en español del test Addenbrooke's Cognitive Examination III para el diagnóstico de demencia. *Neurología*, *35*(2), 82–88. <https://doi.org/10.1016/j.nrl.2017.06.004>
- Carnero-Pardo, C. (2014). ¿Es hora de jubilar al Mini-Mental? *Neurología*, *29*(8), 473–481. <https://doi.org/10.1016/j.nrl.2013.07.003>
- CASEN. (2017). *Adultos Mayores: Síntesis de Resultados*. http://observatorio.ministeriodesarrollosocial.gob.cl/storage/docs/casen/2017/Resultados_Adulto_Mayores_casen_2017.pdf
- Chai, W. J., Abd Hamid, A. I., & Abdullah, J. M. (2018). Working Memory From the Psychological and Neurosciences Perspectives: A Review. *Frontiers in Psychology*, *9*. <https://www.frontiersin.org/article/10.3389/fpsyg.2018.00401>
- Clark, L. R., Schiehser, D. M., Weissberger, G. H., Salmon, D. P., Delis, D. C., & Bondi, M. W. (2012). Specific Measures of Executive Function Predict Cognitive Decline in Older Adults. *Journal of the International Neuropsychological Society*, *18*(1), 118–127. <https://doi.org/10.1017/S1355617711001524>
- Custodio, N., Duque, L., Montesinos, R., Alva-Díaz, C., Mellado, M., & Slachevsky, A. (2020). Systematic Review of the Diagnostic Validity of Brief Cognitive Screenings for Early Dementia Detection in Spanish-Speaking Adults in Latin America. *Frontiers in Aging Neuroscience*, *12*. <https://www.frontiersin.org/article/10.3389/fnagi.2020.00270>
- Custodio, N., Lira, D., Herrera-Perez, E., Montesinos, R., Castro-Suarez, S., Cuenca-Alfaro, J., & Valeriano-Lorenzo, L. (2017). Memory Alteration Test to Detect Amnesic Mild Cognitive Impairment and Early Alzheimer's Dementia in Population with Low Educational Level. *Frontiers in Aging Neuroscience*, *9*, 278. <https://doi.org/10.3389/fnagi.2017.00278>
- de Azeredo Passos, V. M., Giatti, L., Bensenor, I., Tiemeier, H., Ikram, M. A., de Figueiredo, R. C., Chor, D., Schmidt, M. I., & Barreto, S. M. (2015). Education plays a greater role than age in cognitive test performance among participants of the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil). *BMC Neurology*, *15*(1), 191. <https://doi.org/10.1186/s12883-015-0454-6>
- Diamond, A. (2013). Executive Functions. *Annual Review of Psychology*, *64*, 135–168. <https://doi.org/10.1146/annurev-psych-113011-143750>

- Dirnberger, G., & Jahanshahi, M. (2013). Executive dysfunction in Parkinson's disease: A review. *Journal of Neuropsychology*, 7(2), 193–224. <https://doi.org/10.1111/jnp.12028>
- Dubois, B., Slachevsky, A., Litvan, I., & Pillon, B. (2000). The FAB: A Frontal Assessment Battery at bedside. *Neurology*, 55(11), 1621–1626. <https://doi.org/10.1212/wnl.55.11.1621>
- Ebaid, D., Crewther, S. G., MacCalman, K., Brown, A., & Crewther, D. P. (2017). Cognitive Processing Speed across the Lifespan: Beyond the Influence of Motor Speed. *Frontiers in Aging Neuroscience*, 9, 62. <https://doi.org/10.3389/fnagi.2017.00062>
- Fabricio, A. T., Aprahamian, I., & Yassuda, M. S. (2014). Qualitative analysis of the Clock Drawing Test by educational level and cognitive profile. *Arquivos de Neuro-Psiquiatria*, 72, 289–295. <https://doi.org/10.1590/0004-282X20140004>
- Faria, C. de A., Alves, H. V. D., & Charchat-Fichman, H. (2015). The most frequently used tests for assessing executive functions in aging. *Dementia & Neuropsychologia*, 9, 149–155. <https://doi.org/10.1590/1980-57642015DN92000009>
- Ferguson, H. J., Brunson, V. E. A., & Bradford, E. E. F. (2021). The developmental trajectories of executive function from adolescence to old age. *Scientific Reports*, 11(1), 1382. <https://doi.org/10.1038/s41598-020-80866-1>
- Firbank, M., Kobeleva, X., Cherry, G., Killen, A., Gallagher, P., Burn, D. J., Thomas, A. J., O'Brien, J. T., & Taylor, J.-P. (2016). Neural correlates of attention-executive dysfunction in lewy body dementia and Alzheimer's disease. *Human Brain Mapping*, 37(3), 1254–1270. <https://doi.org/10.1002/hbm.23100>
- Fogarty, J., Almklov, E., Borrie, M., Wells, J., & Roth, R. M. (2017). Subjective rating of executive functions in mild Alzheimer's disease. *Aging & Mental Health*, 21(11), 1184–1191. <https://doi.org/10.1080/13607863.2016.1207750>
- García-García-Patino, R., Benito-León, J., Mitchell, A. J., Pastorino-Mellado, D., García García, R., Ladera-Fernández, V., Vicente-Villardón, J. L., Perea-Bartolomé, M. V., & Cacho, J. (2020). Memory and Executive Dysfunction Predict Complex Activities of Daily Living Impairment in Amnesic Multi-Domain Mild Cognitive Impairment. *Journal of Alzheimer's Disease: JAD*, 75(3), 1061–1069. <https://doi.org/10.3233/JAD-191263>
- Goldstein, S., Naglieri, J. A., Princiotta, D., & Otero, T. M. (2014). Introduction: A history of executive functioning as a theoretical and clinical construct. In *Handbook of executive functioning* (pp. 3–12). Springer Science + Business Media. https://doi.org/10.1007/978-1-4614-8106-5_1
- Grandi, F., Martínez-Pernía, D., Parra, M., Olavarria, L., Huepe, D., Alegria, P., Aliaga, Á., Lillo, P., Delgado, C., Tenorio, M., Rosas, R., López, O., Becker, J., Slachevsky, A., Grandi, F., Martínez-Pernía, D., Parra, M., Olavarria, L., Huepe, D., ... Slachevsky, A. (2022). Standardization and diagnostic utility of the Frontal Assessment Battery for healthy people and patients with dementia in the Chilean population. *Dementia & Neuropsychologia*, 16(1), 69–78. <https://doi.org/10.1590/1980-5764-dn-2021-0059>
- Guarino, A., Favieri, F., Boncompagni, I., Agostini, F., Cantone, M., & Casagrande, M. (2019). Executive Functions in Alzheimer Disease: A Systematic Review. *Frontiers in Aging Neuroscience*, 10. <https://www.frontiersin.org/article/10.3389/fnagi.2018.00437>
- Gunning-Dixon, F. M., & Raz, N. (2003). Neuroanatomical correlates of selected executive functions in middle-aged and older adults: A prospective MRI study. *Neuropsychologia*, 41(14), 1929–1941. [https://doi.org/10.1016/s0028-3932\(03\)00129-5](https://doi.org/10.1016/s0028-3932(03)00129-5)
- Harvey, P. D. (2019). Domains of cognition and their assessment. *Dialogues in Clinical Neuroscience*, 21(3), 227–237. <https://doi.org/10.31887/DCNS.2019.21.3/pharvey>
- Henri-Bhargava, A., Stuss, D. T., & Freedman, M. (2018). Clinical Assessment of Prefrontal Lobe Functions. *Continuum (Minneapolis, Minn.)*, 24(3, BEHAVIORAL NEUROLOGY AND PSYCHIATRY), 704–726. <https://doi.org/10.1212/CON.0000000000000609>
- Hutchison, K. A., Balota, D. A., & Duchek, J. M. (2010). The Utility of Stroop Task Switching as a Marker for Early Stage Alzheimer's Disease. *Psychology and Aging*, 25(3), 545–559. <https://doi.org/10.1037/a0018498>
- Ihnen, J., Antivilo, A., Muñoz-Neira, C., & Slachevsky, A. (2013). Chilean version of the INECO Frontal Screening

- (IFS-Ch): Psychometric properties and diagnostic accuracy. *Dementia & Neuropsychologia*, 7, 40–47. <https://doi.org/10.1590/S1980-57642013DN70100007>
- Irwin, H. J. (1978). Input encoding strategies and attenuation of stroop interference. *Australian Journal of Psychology*, 30(2), 177–187. <https://doi.org/10.1080/00049537808256371>
- Junquera, A., García-Zamora, E., Olazarán, J., Parra, M. A., & Fernández-Guinea, S. (2020). Role of Executive Functions in the Conversion from Mild Cognitive Impairment to Dementia. *Journal of Alzheimer's Disease: JAD*, 77(2), 641–653. <https://doi.org/10.3233/JAD-200586>
- Kane, M. J., & Engle, R. W. (2003). Working-memory capacity and the control of attention: The contributions of goal neglect, response competition, and task set to Stroop interference. *Journal of Experimental Psychology. General*, 132(1), 47–70. <https://doi.org/10.1037/0096-3445.132.1.47>
- Kim, H., & Chey, J. (2010). Effects of education, literacy, and dementia on the Clock Drawing Test performance. *Journal of the International Neuropsychological Society*, 16(6), 1138–1146. <https://doi.org/10.1017/S1355617710000731>
- Kim, H. J., Baek, M. J., & Kim, S. (2014). Alternative Type of the Trail Making Test in Nonnative English-Speakers: The Trail Making Test-Black & White. *PLoS ONE*, 9(2), e89078. <https://doi.org/10.1371/journal.pone.0089078>
- Lahav, O., & Katz, N. (2020). Independent Older Adult's IADL and Executive Function According to Cognitive Performance. *OTJR: Occupation, Participation and Health*, 40(3), 183–189. <https://doi.org/10.1177/1539449220905813>
- Lang, L., Clifford, A., Wei, L., Zhang, D., Leung, D., Augustine, G., Danat, I. M., Zhou, W., Copeland, J. R., Anstey, K. J., & Chen, R. (2017). Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ Open*, 7(2), e011146. <https://doi.org/10.1136/bmjopen-2016-011146>
- Lourenço, R. A., Ribeiro-Filho, S. T., Moreira, I. de F. H., Paradela, E. M. P., & Miranda, A. S. de. (2008). The Clock Drawing Test: Performance among elderly with low educational level. *Brazilian Journal of Psychiatry*, 30, 309–315. <https://doi.org/10.1590/S1516-44462008000400002>
- Maillet, D., & Rajah, M. N. (2013). Association between prefrontal activity and volume change in prefrontal and medial temporal lobes in aging and dementia: A review. *Ageing Research Reviews*, 12(2), 479–489. <https://doi.org/10.1016/j.arr.2012.11.001>
- Marshall, G. A., Rentz, D. M., Frey, M. T., Locascio, J. J., Johnson, K. A., & Sperling, R. A. (2011). Executive function and instrumental activities of daily living in MCI and AD. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 7(3), 300–308. <https://doi.org/10.1016/j.jalz.2010.04.005>
- Moheb, N., Mendez, M. F., Kremen, S. A., & Teng, E. (2017). Executive Dysfunction and Behavioral Symptoms Are Associated with Deficits in Instrumental Activities of Daily Living in Frontotemporal Dementia. *Dementia and Geriatric Cognitive Disorders*, 43(1–2), 89–99. <https://doi.org/10.1159/000455119>
- Monteiro, S., Monteiro, B., Candida, M., Adler, N., Campos, C., Rocha, N. B. F., Paes, F., Nardi, A. E., & Machado, S. (2016). Association between depression severity and executive functioning in late-life depression: A systematic review. *MedicalExpress*, 3. <https://doi.org/10.5935/MedicalExpress.2016.06.01>
- Morey, C. C., Elliott, E. M., Wiggers, J., Eaves, S. D., Shelton, J. T., & Mall, J. T. (2012). Goal-neglect links Stroop interference with working memory capacity. *Acta Psychologica*, 141(2), 250–260. <https://doi.org/10.1016/j.actpsy.2012.05.013>
- Morimoto, S. S., Gunning, F. M., Wexler, B. E., Hu, W., Ilieva, I., Liu, J., Nitis, J., & Alexopoulos, G. S. (2016). Executive Dysfunction Predicts Treatment Response to Neuroplasticity-Based Computerized Cognitive Remediation (nCCR-GD) in Elderly Patients with Major Depression. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 24(10), 816–820. <https://doi.org/10.1016/j.jagp.2016.06.010>
- Muñoz-Neira, C., López, O. L., Riveros, R., Núñez-Huasaf, J., Flores, P., & Slachevsky, A. (2012). The technology - activities of daily living questionnaire: A version with a technology-

- related subscale. *Dementia and Geriatric Cognitive Disorders*, 33(6), 361–371. <https://doi.org/10.1159/000338606>
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A Brief Screening Tool For Mild Cognitive Impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>
- Nieto, A., Galtier, I., Hernández, E., Velasco, P., & Barroso, J. (2016). Addenbrooke's Cognitive Examination-Revised: Effects of Education and Age. Normative Data for the Spanish Speaking Population. *Archives of Clinical Neuropsychology*, 31(7), 811–818. <https://doi.org/10.1093/arclin/acw057>
- Olabarrieta-Landa, L., Rivera, D., Galarza-Del-Angel, J., Garza, M. T., Saracho, C. P., Rodríguez, W., Chávez-Oliveros, M., Rábago, B., Leibach, G., Schebela, S., Martínez, C., Luna, M., Longoni, M., Ocampo-Barba, N., Rodríguez, G., Aliaga, A., Esenarro, L., García de la Cadena, C., Perrin, B. P., & Arango-Lasprilla, J. C. (2015). Verbal fluency tests: Normative data for the Latin American Spanish speaking adult population. *NeuroRehabilitation*, 37(4), 515–561. <https://doi.org/10.3233/NRE-151279>
- Paddick, S.-M., Gray, W. K., McGuire, J., Richardson, J., Dotchin, C., & Walker, R. W. (2017). Cognitive screening tools for identification of dementia in illiterate and low-educated older adults, a systematic review and meta-analysis. *International Psychogeriatrics*, 29(6), 897–929. <https://doi.org/10.1017/S1041610216001976>
- Pantzar, A., Laukka, E. J., Atti, A. R., Fastbom, J., Fratiglioni, L., & Bäckman, L. (2014). Cognitive deficits in unipolar old-age depression: A population-based study. *Psychological Medicine*, 44(5), 937–947. <https://doi.org/10.1017/S0033291713001736>
- Pellicer-Espinosa, I., & Díaz-Orueta, U. (2021). Cognitive Screening Instruments for Older Adults with Low Educational and Literacy Levels: A Systematic Review. *Journal of Applied Gerontology*, 07334648211056230. <https://doi.org/10.1177/07334648211056230>
- Persad, C. C., Abeles, N., Zacks, R. T., & Denburg, N. L. (2002). Inhibitory Changes After Age 60 and Their Relationship to Measures of Attention and Memory. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 57(3), P223–P232.
- Protopapas, A., Archonti, A., & Skaloumbakas, C. (2007). Reading ability is negatively related to Stroop interference. *Cognitive Psychology*, 54(3), 251–282. <https://doi.org/10.1016/j.cogpsych.2006.07.003>
- Putcha, D., & Tremont, G. (2016). Predictors of independence in instrumental activities of daily living: Amnestic versus nonamnestic MCI. *Journal of Clinical and Experimental Neuropsychology*, 38(9), 991–1004. <https://doi.org/10.1080/13803395.2016.1181716>
- Ramos-Henderson, M., Ledezma-Dámes, A., López, N., & Machado Goyano Mac Kay, A. P. (2021). Executive functions and functional impairment in Latin seniors suffering from depression. *Aging, Neuropsychology, and Cognition*, 28(4), 543–558. <https://doi.org/10.1080/13825585.2020.1796915>
- Raz, A., Landzberg, K. S., Schweizer, H. R., Zephrani, Z. R., Shapiro, T., Fan, J., & Posner, M. I. (2003). Posthypnotic suggestion and the modulation of Stroop interference under cycloplegia. *Consciousness and Cognition*, 12(3), 332–346. [https://doi.org/10.1016/s1053-8100\(03\)00024-2](https://doi.org/10.1016/s1053-8100(03)00024-2)
- Rivera, D., Perrin, P. B., Stevens, L. F., Garza, M. T., Weil, C., Saracho, C. P., Rodríguez, W., Rodríguez-Agudelo, Y., Rábago, B., Weiler, G., García de la Cadena, C., Longoni, M., Martínez, C., Ocampo-Barba, N., Aliaga, A., Galarza-Del-Angel, J., Guerra, A., Esenarro, L., & Arango-Lasprilla, J. C. (2015). Stroop Color-Word Interference Test: Normative data for the Latin American Spanish speaking adult population. *NeuroRehabilitation*, 37(4), 591–624. <https://doi.org/10.3233/NRE-151281>
- Savva, G. M., & Arthur, A. (2015). Who has undiagnosed dementia? A cross-sectional analysis of participants of the Aging, Demographics and Memory Study. *Age and Ageing*, 44(4), 642–647. <https://doi.org/10.1093/ageing/afv020>
- Scarpina, F., & Tagini, S. (2017). The Stroop Color and Word Test. *Frontiers in Psychology*, 8, 557. <https://doi.org/10.3389/fpsyg.2017.00557>

- Song, Y., & Hakoda, Y. (2015). An fMRI study of the functional mechanisms of Stroop/reverse-Stroop effects. *Behavioural Brain Research, 290*, 187–196. <https://doi.org/10.1016/j.bbr.2015.04.047>
- Stroop, J. R. (1935). Studies of interference in serial verbal reactions. *Journal of Experimental Psychology, 18*(6), 643–662. <https://doi.org/10.1037/h0054651>
- Sudo, F. K., Amado, P., Alves, G. S., Laks, J., & Engelhardt, E. (2017). A continuum of executive function deficits in early subcortical vascular cognitive impairment: A systematic review and meta-analysis. *Dementia & Neuropsychologia, 11*(4), 371–380. <https://doi.org/10.1590/1980-57642016dn11-040006>
- Tartaglia, M. C., Zhang, Y., Racine, C., Laluz, V., Neuhaus, J., Chao, L., Kramer, J., Rosen, H., Miller, B., & Weiner, M. (2012). Executive dysfunction in frontotemporal dementia is related to abnormalities in frontal white matter tracts. *Journal of Neurology, 259*(6), 1071–1080. <https://doi.org/10.1007/s00415-011-6300-x>
- Tavares-Júnior, J. W. L., de Souza, A. C. C., Alves, G. S., Bonfadini, J. de C., Siqueira-Neto, J. I., & Braga-Neto, P. (2019). Cognitive Assessment Tools for Screening Older Adults With Low Levels of Education: A Critical Review. *Frontiers in Psychiatry, 10*, 878. <https://doi.org/10.3389/fpsy.2019.00878>
- van Boxtel, M. P. J., ten Tusscher, M. P. M., Metsemakers, J. F. M., Willems, B., & Jolles, J. (2001). Visual Determinants of Reduced Performance on the Stroop Color-Word Test in Normal Aging Individuals. *Journal of Clinical and Experimental Neuropsychology, 23*(5), 620–627. <https://doi.org/10.1076/jcen.23.5.620.1245>
- Véliz García, Ó., Calderón Carvajal, C., Beyle Sandoval, C., Véliz García, Ó., Calderón Carvajal, C., & Beyle Sandoval, C. (2020). Propiedades Psicométricas del Addenbrooke's Cognitive Examination III: Estructura Factorial, Análisis TRI y Utilidad Diagnóstica para la detección de demencia en Atención Primaria de Salud. *Revista Médica de Chile, 148*(9), 1279–1288. <https://doi.org/10.4067/S0034-98872020000901279>
- Yun, J.-Y., Lee, D. Y., Seo, E. H., Choo, I. H., Park, S. Y., Kim, S. G., & Woo, J. I. (2011). Neural Correlates of Stroop Performance in Alzheimer's Disease: A FDG-PET Study. *Dementia and Geriatric Cognitive Disorders Extra, 1*(1), 190–201. <https://doi.org/10.1159/000329517>
- Zimmermann, N., Parente, M. A. de M. P., Joannette, Y., & Fonseca, R. P. (2014). Unconstrained, phonemic and semantic verbal fluency: Age and education effects, norms and discrepancies. *Psicologia: Reflexão e Crítica, 27*, 55–63. <https://doi.org/10.1590/S0102-79722014000100007>