UNIVERSIDAD SAN JORGE

Facultad de Ciencias de la Salud

Programa de Doctorado en Ciencias de la Salud



Estilo de vida de las personas supervivientes de un ictus: actividad física y participación en la vida cotidiana

Cristina de Diego Alonso

TESIS DOCTORAL

Villanueva de Gállego, Julio 2024



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Entregada por

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Villanueva de Gállego, Julio 2024

“Investigar es ver lo que todo el mundo ha visto
y pensar lo que nadie ha pensado”

Albert Szent-Györgi

“Quien siga su brújula interior,
llegará a la meta con los ojos cerrados”

Tessa Randau

“Aprender a volar exige muchas horas de suelo”

Antonio Carreño

AGRADECIMIENTOS

El proceso de elaboración de la Tesis Doctoral ha sido complejo, rodeado de un sinfín de variedad de emociones, que por suerte he disfrutado muchísimo. Ha sido una etapa enormemente enriquecedora en todos los sentidos.

Gracias por haberme encontrado con personas muy distintas y en diferentes contextos. Ha sido un profundo aprendizaje sobre las innumerables percepciones ante una misma situación, una interacción multifactorial en constante cambio.

La motivación por investigar empezó hace bastante tiempo, por suerte la decisión de iniciar esta tesis llegó el momento adecuado y en un entorno favorecedor. Esto permitió que se realizara, gracias a cada una de estas personas que lo han hecho posible.

La esencia de estas tesis nace de las vivencias en la asistencia clínica de "neuro". Es por ello que, quiero agradecer a Bettina Paeth por darme la oportunidad de "explorar liándola desde la inexperiencia". Gracias a Carmen Enguita "por dejarme hacer". Gracias a cada una de las personas a las que he acompañado y a sus familiares. Nuestras intensas horas de tratamiento, han sido claves en el proceso de estas tesis y han contribuido a la interpretación de los resultados.

Mi primer contacto con la investigación fue a través del máster de neurociencias, en la Universidad Autónoma de Barcelona. Junto a mi compi Silvia Puig, fuimos capaces de sobrevivir al "máster del universo" rodeadas de cascadas moleculares, experimentos celulares y animales. Afortunadamente Xavier Navarro "se hizo cargo" de 2 apasionadas de la terapia ocupacional y la fisioterapia, que quería evidenciar el efecto de intervenciones individualizadas, sin un protocolo estandarizado en personas que no hubieran cumplido criterios en cualquier otro estudio. Gracias Xavi, por iniciarme en el mundo de la investigación y hacerme ver la importancia de justificar cada intervención.

Gracias a mis compañeros de la Universidad San Jorge, por los raticos de conversación y risas en cafetería, pasillos y compartiendo asignaturas. Una selección muy "peculiar" de personas de alto nivel, cada uno *cracks* de vuestro campo, que habéis sido fuente de inspiración para mí.

Gracias a mis directores, por guiarme y acompañarme durante esta aventura de querer aprender a investigar.

Javier, gracias por aceptar ser mi director de tesis y abrirme las puertas del mundo de la investigación cualitativa, por intentar ayudarme en un proceso de triple triangulación con doble tirabuzón. Por intentar encontrar tiempo para responder a mis consultas, a pesar de estar absorbido por tus cargos de gestión donde siempre hay líos que atender.

Gracias a Pablo Bellosta, por una larguísima conversación sobre una loca idea de una investigación a lo grande, a raíz de la cual te convertiste en mi mentor en cada uno de los pasos de estas tesis. Piedra angular del diseño metodológico, maestro profundamente entusiasmado por la investigación. Gracias por las largas reuniones, innumerables emails y acompañamiento en un proceso de aprendizaje complejo e intenso. Por aportarme siempre posibles soluciones a los obstáculos en el camino. Gracias por cumplir uno de mis deseos, aprender a investigar y disfrutar en el proceso.

Gracias Jorge Alegre, por responder a una llamada un 24 de diciembre para pedirte opinión sobre temas para iniciarme en el mundo de la investigación. Por responder a cada uno de mis emails, WhatsApp y llamadas para consultarte y debatir sobre la visión de nuestra disciplina de Terapia Ocupacional sobre: *"¿Qué es la participación y participar?"*. Que suerte tenerte a mi lado en esta investigación, a pesar de que por circunstancias de la vida hayas estado en un segundo plano.

Gracias al equipo "MOTUS", por vuestro granito de arena en este proceso. Contar con la compañía de un grupo de investigación como vosotros facilita bastante el camino. Gracias por haber dejado un sendero marcado por el que es más difícil perderse. Gracias a "*la magia de la cuali*" de Almu y Patri, la experiencia técnica de Víctor y a las correcciones y puntualizaciones de Julia, Mapi, Rafa y Almudena.

Gracias Natalie Fini por responder a mi email y formar parte de esta investigación. Gracias por tu forma sutil, pero directa de indicarme los cambios a realizar siempre desde la dulzura, las palabras de ánimo y reconocimiento del proceso de aprendizaje.

Gracias a Laura Vidaña, por abrirme una ventana y ponerme en contacto con las creadoras de SDO-OB, Mona Eklund y Jenny Hultqvist. Gracias a Mona por aportar un matiz de alta precisión a cada término y concepto sobre la participación desde tu experiencia de Terapia Ocupacional. Ha sido un aprendizaje de reflexión muy profundo e interesantes debates.

Mi enorme GRACIAS a todas las personas que han creído y confiado en este "super proyecto loco", diseñado a lo grande como dice un incansable compañero Luc Vercuysse "*The sky is the limit*" que me contagió su inquietud sobre la esencia de la ocupación humana.

Gracias a todos los "profesionales colaborades" sin los cuales esta investigación difícilmente se podría haber realizado. Por aportar innumerables comentarios constructivos en cada una de las formaciones, reuniones y conversaciones mantenidas. Gracias a cada uno de vosotros: Inés, Cortés Cabeza, Claudia Marín Marín, Rebeca, Yebra Vilarchao ,Ana, Conte Lamenca, Diana Ruiz Ramos, Lilian, Le Roux, Sara, Beltrán Roche, Elena, Sanz Sanza, Leyre, Leceaga Gaztambide, Carina, Salgueiro, Fernando, Cuesta Ruiz,Javier, Harguindey, Andrea, Yerro Astrain, Enrique, Villa Berges, Paz Cristina, Sánchez Lecina, Lourdes, Martín Gros, Paloma, Rodríguez Escudero, María Carmen, Grácia Sen, María Pilar, Pardo Sanz, Alicia, Tornero Navarro, Juan Luis, Abeledo Alcón, Lucía, Díez Fuentes, Verónica, Montoya Murillo, Laura, Ares Barge, Natalia Muiño, Beatriz, Martín Lamata.

Gracias a los centros e instituciones y profesionales autónomos que abrieron sus puertas a esta investigación y se tomaron con paciencia los trámites burocráticos. Gracias a cada uno de ellos: ADACECO, AENO, AGREDACE, AIDA, ASPAYM, CENNER, Centro Neurorehabilitación, CIRON, Fundación Pita López, Grupo 5 Cian Pamplona, Grupo 5 Cian Zaragoza, Hospital Provincial Sagrado Corazón de Jesús, Hospital Universitario San Jorge, INEURO, Juan Luis, Abeledo Alcón, LEZCANO FISIOTERAPIA, NEUFIS, NEURAXIS, NEUROESPLUGUES, Centro Fisioterapia El Carmen.

Gracias a las 140 personas y sus familiares que han formado parte de la investigación. Largas conversaciones en persona, video llamada y teléfono. Gracias por abrirme vuestro corazón lleno de vivencias de "*supervivientes de un ictus".* Gracias por vuestra aportación a la ciencia.

Gracias a las ayudas, becas y premios que han contribuido con su granito de arena a esta investigación: Edelvives, CITO, COPTOA y COPTOCAM.

Gracias a mi familia por contribuir a ser lo que soy ahora y hasta donde he llegado. Por una educación de mis padres basada en la constancia y perseverancia, cualidades que me han sido de gran utilidad durante este proceso. Gracias por convencerme de estudiar Terapia Ocupacional y Fisioterapia a una entusiasmada de la alfarería y las manualidades. Con esta tesis, se cierra un tema inacabado.

Gracias a mi yaya Ángeles, fuente de inspiración, inquietud por la vida, insaciable aprendizaje, ejemplo de adaptación constante en las diferentes fases de la vida, potenciadora de ilusión, conversación y escucha. Siento que de algún modo has estado ahí.

Gracias a la logística de "*Las López*", que me ha permitido resetear y recargar energía.

Gracias Ángel por estar ahí, cada día, por apoyarme durante este camino y escucharme en modo disco rayado sobre cada nuevo avance o retroceso de esta tesis. Gracias por entender que era el momento para iniciar esta tesis, por hacerme reír y arroparme cuando lo he necesitado. Por la logística que me ha permitido llegar a finalizar este proceso.

Gracias a "*mis chicos*" Adrián y Martín intensos exploradores de la vida que me mantienen alerta 24/7 365. Pequeñas personas que no dejan de sorprenderme día a día con sus preguntas e inquietudes. Pequeñas "*almas creativas*" que pusieron música y letra junto a Ángel a este proceso de "*el doctorado*" para motivarme. Capaces de pasar de modo "*fiesta de cumpleaños*" a modo "*silencio absoluto*" si entro en una videoconferencia.

Gracias a Estela por su "*reajuste con el universo*", mis compis de "Reus sisters", "cole", "de Laredo lin" y "reencuentro Barcelona" por haber compartido alguno de los momentos que han formado parte de este proceso.

Gracias a todos los que me han dado la oportunidad de equivocarme y acompañarme en el proceso de aprender de ello, a las personas que ya no están o sus caminos han llevado rumbos diferentes, todas ellas también son y han sido necesarias y han contribuido sin saberlo.

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GLOSARIO DE SIGLAS Y ACRÓNIMOS

6MTW: *6-Metre Timed Walk*

6MWT: *6-minute walk test*

ACS: *The Activity Card Sort*

AF: actividad física

AFM: actividad física moderada

AFMV: combinación de actividad física moderada-vigorosa

AFV: actividad física vigorosa

BI: *The Barthel Index*

CIF: Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud

EQ-5D-5L: *The 5-level EQ-5D version*

IPAQ: *The International Physical Activity Questionnaire*

IPAQ-SF: *The International Physical Activity Questionnaire- Short Form*

Kcal: Kilocalorías

Kcal/min: Kilocalorías quemadas por minuto

METs: *Metabolic Equivalents of Task*

OMS: Organización Mundial de la Salud

SDO-OB: *The Satisfaction with Daily Occupations-Occupational Balance*

SIS: *The Stroke Impact Scale*

RESUMEN

A nivel mundial el número de personas supervivientes de un ictus ha aumentado en los últimos años, datos que también se reflejan en España. Se espera que siga incrementándose progresivamente este número si no se realizan intervenciones centradas en su prevención, así como enfocadas a reducir el impacto de sus secuelas. Se sabe que las personas supervivientes de un ictus tienen un estilo de vida sedentario y requieren de varios años para retomar la participación en algunas actividades de la vida cotidiana.

Hasta ahora, no se ha prestado especial atención a las relaciones entre las variables de actividad física y participación, así como la experiencia individual de cada persona después del ictus y los factores que pueden influir en este estilo de vida. Además, no se disponen de herramientas de valoración que hayan demostrado buenas propiedades psicométricas para aportan datos sobre dichas variables.

El objetivo principal de esta Tesis Doctoral fue explorar multidimensionalmente el estilo de vida de las personas con alto nivel de funcionalidad que habían tenido un ictus al menos hace 6 meses, en relación con su nivel de actividad física y participación en la vida cotidiana. A través de la literatura disponible y la situación de las personas que residen en diversas regiones de España, además de analizar las propiedades psicométricas de las herramientas de valoración para la obtención de estos datos. Para llevar a cabo este objetivo se realizaron varios estudios que aparecen reflejados en los artículos científicos.

Los principales hallazgos de la presente Tesis Doctoral fueron: i) En los supervivientes de un ictus existe una correlación entre el tiempo de actividad física y la participación en las actividades de la vida diaria en participantes durante los primeros 6 meses después del ictus, y entre el tiempo de actividad física y la participación en todas las actividades de la vida cotidiana en participantes más allá de los 6 meses posteriores al ictus. ii) Existe una gran heterogeneidad en las investigaciones realizadas en supervivientes de un ictus focalizadas en analizar el nivel de actividad física y participación. iii) La herramienta de valoración *The International Physical Activity Questionnaire-Short Form* demostró una adecuada validez aparente, siendo recomendable que sea administrada por evaluadores con experiencia clínica y previamente entrenados. iv) *The International Physical Activity Questionnaire-Short Form* demostró una adecuada validez de constructo, presentando correlaciones

"moderadas" a "fuertes" con la pulsera de monitorización de actividad Fitbit Inspire 2, y correlaciones "débiles" a "moderadas" con el test de velocidad de la marcha *6-Metre Timed Walk*, además la estabilidad test-retest *The International Physical Activity Questionnaire-Short Form* fue de "moderada" a "excelente". v) *The International Physical Activity Questionnaire-Short Form* es un cuestionario autoinformado de bajo coste y rápida administración, válido para el cribado de los niveles de actividad física y el cumplimiento de los niveles de actividad física recomendados por la Organización Mundial de la Salud. vi) La herramienta de valoración *The Satisfaction with Daily Occupations-Occupational Balance* presentó una consistencia interna, validez convergente aceptable. vii) *The Satisfaction with Daily Occupations-Occupational* tuvo una buena fiabilidad test-retest, discriminó entre grupos con y sin cuidadores y no tuvo efectos de suelo o techo. viii) *The Satisfaction with Daily Occupations-Occupational* puede ser un instrumento de referencia para abordar el nivel de actividad, la satisfacción y el equilibrio en la participación en actividades en personas supervivientes de un ictus. ix) El nivel de actividad física autoinformada a través *The International Physical Activity Questionnaire-Short Form* y monitorizado a través del dispositivo Fitbit Inspire 2 en supervivientes de ictus con un alto nivel funcional tiene una correlación con las actividades instrumentales de la vida diaria medidas con *Activity Card Sort* y el nivel de participación medido con *the Satisfaction with Daily Occupations-Occupational Balance*. x) Las personas supervivientes de un ictus con un buen nivel funcional que residen en España destacaron la perspectiva individual sobre la readaptación a la actividad y ejercicio físicos. Destacaron la importancia de las secuelas que limitan esta readaptación, las preferencias individuales, el estilo de vida activa previo, así como las múltiples influencias del entorno sobre este comportamiento cuando las secuelas del ictus no limitan la deambulación y por tanto la posibilidad de movimiento. xi) El retorno a la participación tras un ictus es una experiencia individual compleja con influencias multifactoriales entre las que se resaltó la historia ocupacional previa al ictus, la percepción de uno mismo en el transcurso de la recuperación, la capacidad de aceptación y adaptación y apoyo del contexto familiar y social, así como la búsqueda de formas alternativas de adaptación al entorno.

Los resultados incorporaron relevante conocimiento a la evidencia científica actual indicando que existe una relación entre el nivel de actividad física y participación, demostrando que hay herramientas de valoración capaces de abarcan la complejidad de ambos dominios sobre los que es importante contemplar la experiencia individual de cada

persona. Sería recomendable que dicha relación y circunstancias individuales se consideren en la elaboración de futuros planes de intervención en personas supervivientes de un ictus con un alto nivel funcional además de analizar su influencia sobre los factores de riesgo modificables y la calidad de vida.

ABSTRACT

The number of stroke survivors worldwide has increased in recent years, a figure that is also reflected in Spain. It is expected to continue to increase progressively if interventions focused on prevention and reducing the impact of its sequelae are not carried out. Stroke survivors are known to have a sedentary lifestyle and require several years to resume participation in some activities of daily living.

No particular attention has been paid so far to the relationships between the variables of physical activity and participation, as well as the individual experience of each person after stroke and the factors that may influence this lifestyle. Furthermore, there are no assessment tools available that have demonstrated good psychometric properties to provide data on these variables.

The principal purpose of this Doctoral Thesis was to explore multidimensionally the lifestyle of people with a high functional level who have had a stroke at least 6 months ago, in relation to their level of physical activity and participation in daily life. Through available literature and situation of people residing in different Spanish regions, besides analysing the psychometric properties of assessment tools to obtain these data. To carry out this aim, several studies were carried out and are reflected in the scientific articles.

The principal findings of this doctoral thesis were: i) There is a correlation between physical activity time and participation in activities of daily living in stroke survivors during the first 6 months after stroke, and between physical activity time and participation in all activities of daily living in participants beyond 6 months post-stroke. ii) There is a large heterogeneity in the research conducted in stroke survivors focused on analysing the level of physical activity and participation. iii) The International Physical Activity Questionnaire-Short Form assessment tool showed adequate face validity, being advisable that it be administered by clinically experienced and previously trained evaluators. iv) The International Physical Activity Questionnaire-Short Form demonstrated adequate construct validity, showing "moderate" to "strong" correlations with the Fitbit Inspire 2 activity monitoring wristband, and "weak" to "moderate" correlations with the 6-Metre Timed Walk speed test, and the test-retest stability of The International Physical Activity Questionnaire-Short Form was "moderate" to "excellent".

v) The International Physical Activity Questionnaire-Short Form is a self-report questionnaire low cost and quick administration, valid for screening physical activity levels and compliance with the physical activity levels recommended by the World Health Organization. vi) The Satisfaction with Daily Occupations-Occupational Balance assessment tool showed acceptable internal consistency and convergent validity. vii) The Satisfaction with Daily Occupations-Occupational had good test-retest reliability, discriminated between caregiver and non-caregiver groups, and showed no floor or ceiling effect. viii) The Satisfaction with Daily Occupations-Occupational may be a reference instrument to address activity level, satisfaction, and balance in activity participation in stroke survivors. ix) The level of physical activity self-reported through The International Physical Activity Questionnaire-Short Form and monitored through the Fitbit Inspire 2 device in stroke survivors with a high functional level correlates with instrumental activities of daily living measured with the Activity Card Sort and the level of participation measured with the Satisfaction with Daily Occupations-Occupational Balance. x) Stroke survivors with a high functional level residing in Spain highlighted the individual perspective on readaptation to physical activity and physical exercise. They emphasized the importance of the sequelae that limit readaptation, individual preferences, previous active lifestyle, as well as the multiple influences of the environment on this behavior when the sequelae of the stroke do not limit ambulation and therefore the possibility of movement. xi) Return to participation after stroke is a complex individual experience with multifactorial influences, among which the occupational history prior to stroke, self-perception in recovery, the capacity for acceptance and adaptation and support from the family and social context, as well as the search for alternative ways of adapting to the environment were highlighted.

The results included relevant knowledge to the current scientific evidence showing that a relationship between the level of physical activity and participation exists and demonstrating that there are assessment tools capable of encompassing the complexity of both domains in which the individual experience of each person should be taken into consideration. It would be recommendable that this relationship and individual circumstances be considered in the elaboration of future intervention plans for stroke survivors with a high functional level, besides analysing their influence on modifiable risk factors and quality of life.

PREÁMBULO

La memoria de Tesis Doctoral que estructura en 10 capítulos.

En el presente preámbulo se exponen los principales aspectos que serán abordados en cada uno de los capítulos que serán abordados en profundidad en cada uno de ellos. En el **CAPÍTULO 1. INTRODUCCIÓN** se revisa el conocimiento sobre el ictus y el impacto sobre el estilo de vida de la persona en relación a la actividad física y la participación, incluyendo información sobre las herramientas de valoración de ambas variables. **CAPÍTULO 2. JUSTIFICACIÓN**, se aborda la necesidad de realizar cada uno de los estudios para dar respuesta al vacío en la literatura. En el **CAPÍTULO 3. HIPÓTESIS Y OBJETIVOS** se exponen las hipótesis de cada uno de los estudios realizados junto al objetivo general y específicos de cada uno de los estudios realizados. En el **CAPÍTULO 4. MATERIAL Y MÉTODOS** se exponen el procedimiento realizado en cada uno de los estudios, diseños, participantes y las herramientas de valoración utilizadas. En el **CAPÍTULO 5. RELACIÓN DE ARTÍCULOS** se expone el compendio de artículos que componen la presente Tesis Doctoral e incluye cada uno de los artículos en su formato de publicación o envío a la revista. En el **CAPÍTULO 6. RESUMEN DE RESULTADOS** se incorpora en una tabla los principales resultados de los artículos. En el **CAPÍTULO 7. DISCUSIÓN GENERAL** se abordan los diferentes hallazgos de los estudios realizados en relación con la evidencia disponible hasta la fecha. Posteriormente se exponen las principales implicaciones clínicas de los estudios planteados. En el **CAPÍTULO 8. LIMITACIONES** se indican los aspectos que afectan a la generalización de los resultados encontrados. En el **CAPÍTULO 9. FUTURAS LÍNEAS DE INVESTIGACIÓN** se exponen nuevas hipótesis que plantean futuras investigaciones en base a los hallazgos encontrados. En el **CAPÍTULO 10. CONCLUSIONES**, se presentan las principales conclusiones extraídas de los estudios realizados. Finalmente, en el **CAPÍTULO 11. ANEXOS** se incluyen los artículos de protocolo de la revisión sistemática y el proyecto de investigación Part&Sed-Stroke.

CAPÍTULO 1. INTRODUCCIÓN

1.1. Ictus y sus secuelas en las personas supervivientes

1.1.1. Definición

La Organización Mundial de la Salud (OMS) definió en 1970 el ictus como *"desarrollo rápido de signos clínicos de alteración focal (o global) de la función cerebral, con una duración de más de 24 horas o que provoca la muerte, sin causa aparente que no sea de origen vascular"* [1]. Esta definición fue actualizada posteriormente por *The American Heart Association* y *The American Stroke Association* en base a los nuevos conocimientos científicos como *"déficit neurológico atribuido a una lesión focal aguda del sistema nervioso central (incluyendo lesión cerebral, medular o retiniana) por una causa vascular, incluyendo el infarto cerebral, hemorragia intracerebral y hemorragia subaracnoidea cuyos síntomas persisten más de 24 horas o hasta la muerte"* [2]. Concretamente, los diferentes tipos de ictus pueden agruparse en accidente cerebrovascular isquémico (episodio de disfunción neurológica causado por un infarto cerebral, medular o retiniano focal de una estructura venosa o arterial, que ocasiona su obstrucción disminuyendo la llegada de sangre a las zonas afectadas), infarto silencioso del sistema nervioso central (evidencia neuropatológica o de imagen de infarto del sistema nervioso central, sin antecedentes de disfunción neurológica aguda atribuible a la lesión) o accidente cerebrovascular hemorrágico (acumulación focal de sangre en el parénquima cerebral o en el sistema ventricular que no se debe a un traumatismo). A su vez, el accidente cerebrovascular hemorrágico puede clasificarse en hemorragia intracerebral no traumática (espontánea) y hemorragia subaracnoidea no traumática (aneurisma espontáneo) [2].

1.1.2. Datos epidemiológicos

La revisión sistemática más actualizada hasta la fecha publicada en 2021 en la prestigiosa revista Lancet destacó que en 2019, el ictus tuvo una prevalencia a nivel mundial de 101 millones y 6,55 millones de muertes, y una incidencia de 12,2 millones de ictus de los cuales el 62,4% correspondieron a ictus isquémicos, 27,9% a hemorragias intracerebrales y 9,7% a hemorragias subaracnoideas [3]. Aunque en 2019 a nivel mundial, el número absoluto de años de vida ajustados por discapacidad debidos al ictus en varones (76,9 millones) superó al de mujeres (66,4 millones), las estimaciones puntuales en incidencia y prevalencia fueron mayores en las mujeres que en los hombres, sin grandes diferencias en el número de muertes relacionadas con el ictus entre sexos [3]. El último informe de 2019 aportado por la Sociedad Española de Neurología, indicó que en 2006 la prevalencia estimada de ictus fue de 6,4% en población de 70 años o más, siendo mayor en hombres (7,3%) que en mujeres (5,6%) y más elevada en zonas urbanas (8,7%) que rurales (3,8%) [4]. Concretamente, según el estudio IBERICTUS la incidencia de ictus alcanzó los 187,4 casos por cada 100.000 habitantes [5].

Cabe destacar que el número absoluto de ictus en todo el mundo aumentó un 70% [67-73] de 1990 a 2019 [3] y se prevé que dicha incidencia se incremente un 35% entre 2015 y 2035 debido especialmente, al aumento de la esperanza de vida de la población [4]. Según las previsiones de la OMS, a nivel global una de cada cuatro personas mayores de 25 años sufrirá un ictus a lo largo de su vida [3,6]. En concreto, se estima que en 2025 en Europa, 1.5 millones de personas sufrirán un ictus [7], aumentando progresivamente la carga absoluta del ictus en Europa a lo largo de los próximos 30 años debido a un incremento del 27% en la supervivencia de las personas que la sufren [8].

En este sentido, el ictus es actualmente la segunda causa de muerte en los países desarrollados después de la cardiopatía isquémica [3,9], afectando principalmente a adultos mayores de 65 años [3,10]. En 2018, el ictus fue la segunda causa de muerte en España, la tercera en hombres y la primera en mujeres [4]. Donde los datos analizados arrojan una tasa de mortalidad asociada al ictus ajustada por edad de 25,1 por cada 100.000 habitantes (28,7 en hombres y 21,9 en mujeres) [4]. Lo cual implica que en España cada año mueren en torno a 27.000 personas a causa de un ictus [4].

1.1.3. Las secuelas del ictus

Los supervivientes de un ictus, presentan diversas secuelas, entre las que se encuentras deficiencias sensoriomotoras, cognitivas y emocionales [2,11] que impactan sobre su autonomía e independencia. En concreto, según indica en 2021 Kennedy et al. [12] dos tercios de estas personas muestran dificultades para caminar de forma independiente, incluso después de 3 meses posteriores al ictus. Estas secuelas limitan su capacidad para realizar actividades cotidianas y ocasionan restricciones en la participación [13], principalmente en actividades del área del autocuidado, el trabajo, el ocio y tiempo libre, y las actividades sociales [13-18] cuyo retorno a la participación plena requiere de más de 6 meses, llegando a necesitar varios años tal y como refleja Della Vecchia et al. (2021) [19]. Es por ello por lo que, actualmente el ictus se sitúa como la tercera causa de discapacidad a nivel mundial según Feigin et al. (2022) [20], con una prevalencia de 143 millones de personas, de las cuales 512.380 corresponden a España. Cabe destacar que en 2019 se alcanzó una incidencia anual de 61.102 personas españolas supervivientes de un ictus con algún grado de discapacidad [3]. Es por ello por lo que, un alto porcentaje de supervivientes de un ictus que vive en casa necesita un alto nivel de apoyo por parte de familiares y asistentes contratados de forma privada, que ejercen el rol de cuidador principal.

1.1.4. Reorganización del sistema nervioso central

Es necesario tener en cuenta que, las nuevas actualizaciones sobre neurociencia reafirman que el proceso de reorganización neuronal que tiene lugar tras una lesión como el ictus. Es un proceso continuo, en el que intervienen diversos mecanismos de neuroplasticidad, en función del tiempo transcurrido desde el ictus o las secuelas generadas [21-23]. Cabe recordar que hace años quedó desterrada la hipótesis que afirmaba que, tras los 6 meses posteriores al ictus, la persona no tenía posibilidad de experimentar cambios [21,22,24,25]. Por lo tanto, actualmente se sabe que todas las personas supervivientes de un ictus tienen cierto potencial para generar cambios en base a ciertos factores predictores (p. ej., gravedad o situación funcional durante las primeras horas, localización de la lesión o edad) [26-30] y el entorno enriquecido en el que se encuentren [31].

En este sentido, el subgrupo de personas supervivientes de un ictus con una evolución de más de 6 meses, que reside en su propio domicilio y presenta alta capacidad funcional asociada a una marcha independiente y sin dificultades de procesamiento cognitivo ni de

comunicación, tiene un importante potencial dentro del sistema sanitario para comprometerse activamente en la adopción de estilos de vida saludables, reduciendo así el riesgo de recurrencia del ictus [32,33] y alcanzando un alto nivel de autonomía e independencia.

1.1.5. Gasto socioeconómico y sanitario

El ictus se considera una enfermedad de alta complejidad en términos económicos, debido a las secuelas que ocasiona a los supervivientes. Estos requieren de un tratamiento prolongado, al que se destina aproximadamente el 34% del gasto sanitario total mundial según la revisión sistemática de Rochmah et al. (2021) [34]. Siendo en 2015 el coste total asociado al ictus en España de 2.908 millones de euros. Alcanzando 623 millones de euros en 2017 destinados al coste total anual de 93.022 hospitalizaciones por ictus. Sin embargo, la mayor parte de los costes reales se dan principalmente tras esta hospitalización, consistiendo en los cuidados informales cuyo gasto repercute principalmente en las familias. Asimismo, según el informe estadístico de 2015 sobre las enfermedades cardiovasculares de *The European Heart Network*, los cuidados informales y las pérdidas de productividad laboral (debidas a la muerte o a la discapacidad) suponían de media 35 € al día por ciudadano.

En este sentido, en 2040-2050 se estima un aumento significativo en el número de supervivientes de un ictus en todo el mundo [8,35-41]. Implicando consecuentemente un incremento en el número de personas que presentarán discapacidad cuya situación elevará los costes sanitarios y socioeconómicos [3,34,42]. Entre estos gastos, la OMS ha indicado que debería estar contemplada la neurorrehabilitación, tanto en fases iniciales como a largo plazo según Cierza et al. (2021) [43], con el objetivo de reducir las secuelas, e incrementar la autonomía y la independencia [44]. Especialmente, habiendo quedado demostrado que el retraso en el inicio del tratamiento neurorrehabilitador empeora tanto el pronóstico funcional como la discapacidad de las personas, y se asocia con una mayor tasa de institucionalización al alta. Siendo del 5,4% cuando el tratamiento se inicia en los 15 primeros días, y del 22,7% cuando se inicia más allá de 45 días tras el ictus [4].

1.2. Factores de riesgo cardiovascular

1.2.1. Factores de riesgo en personas sanas

En 2019, *The Global Burden of Disease* identificó 19 factores de riesgo causantes del 87,0% de la discapacidad ocasionada por el ictus. Concretamente, los cinco principales factores de riesgo específicos relacionados con la muerte y discapacidad por ictus fueron: una presión arterial sistólica elevada (55,5%), un índice de masa corporal elevado (24,3%), una glucosa plasmática en ayunas elevada (20,2%), la contaminación por partículas ambientales (20,1%), y el tabaquismo 17,6%) [3] (*Figura 1).*

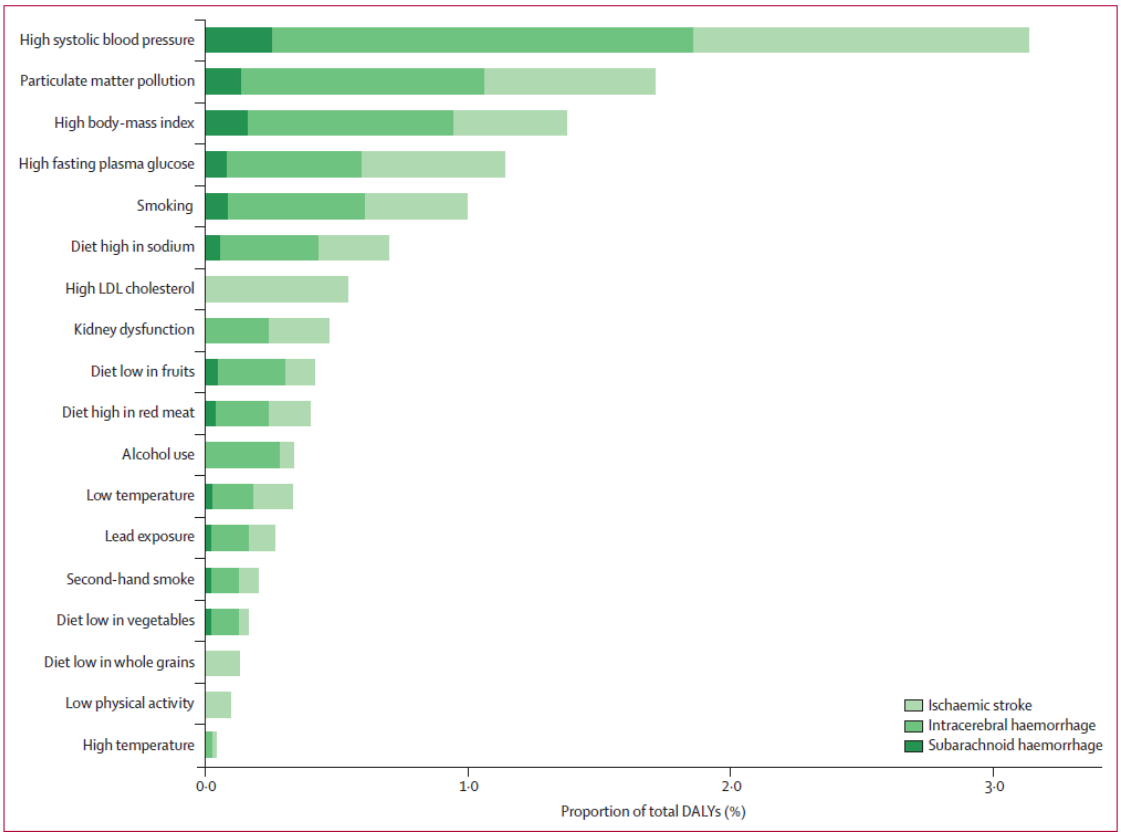


Figura 1*. Proporción de años totales de vida ajustados a la discapacidad de ictus atribuibles a los factores de riesgo. Información extraída de The Global Burden of Disease 2019 Stroke Collaborators. Global, regional, and national burden of stroke and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet Neurol [3]. Open Access article under the CC BY 4.0.*

Cabe destacar que la inactividad física está asociada con hasta un 20-30% del aumento de riesgo de muerte [45], y según el estudio INTERSTROKE [46] es uno de los cinco factores clave que está relacionada con el 80% de la carga global de ictus [47]. No obstante, alrededor del 31% de la población mundial se clasifica como físicamente inactiva, es decir, que no alcanzan las recomendaciones de la OMS [48] de actividad física (AF) [49]. En este aspecto, el tiempo que la persona pasa sentada es un factor de riesgo relacionado con la mortalidad por enfermedades cardiovasculares [50].

Es necesario tener en cuenta que, las poblaciones adultas que cumplen las recomendaciones de AF de la OMS muestran un menor riesgo de muerte y de desarrollar enfermedades no transmisibles (p. ej., enfermedades cardiovasculares, cáncer o diabetes) [51]. Sin embargo el 33% de la población mundial permanece físicamente inactiva según Bull et al. (2020) [52], y este porcentaje aumenta hasta el 81% entre los supervivientes de un ictus [53].

1.2.2. Factores de riesgo en supervivientes de un ictus

En concreto se sabe que, la AF reduce el riesgo de ictus en un 25% [54] y tiene un efecto positivo sobre todos los factores de riesgo modificables de recurrencia del ictus [55,56]. Se ha demostrado que, incluso con dosis de AF inferiores a las recomendadas [57], se consiguen beneficios cardiometabólicos [58], reducción de secuelas [59], recuperación de la independencia y aumento de la participación [56], todo lo cual contribuye a aumentar la calidad de vida en los supervivientes de un ictus [60].

En este sentido, los supervivientes de un ictus tienen un 30% más de riesgo de sufrir un nuevo ictus [61], de tal modo que uno de cada seis tendrá un nuevo ictus durante el primer año, incrementando a uno de cada tres transcurridos los primeros tres años [62,63]. Afortunadamente, es de esperar que estos datos no sigan aumentando en este siglo gracias a la prevención secundaria [62,63] y el auge del interés en la investigación, y por consiguiente de la información para controlarlo a través de los factores modificables ligados al estilo de vida. El control de los factores de riesgo modificables como el tabaquismo, la obesidad, la diabetes de tipo 2, la hipertensión, el colesterol alto, la inactividad física y la ingesta alimentaria [64] guardan una relación no sólo con la prevención primaria, sino también con la secundaria [62,63] a través de los estilos de vida saludables [65,66]. Según recientes investigaciones, los factores de riesgo modificables pueden diferir entre las áreas rurales y urbanas [67-70].

En concreto, la realización de AF de forma regular [56,71,72] tras el ictus puede contribuir a la prevención secundaria, por su efecto positivo sobre todos los factores de riesgo modificables de una recidiva (p. ej., hipertensión arterial, glucosa en sangre y niveles de colesterol) [55,73-77]. Especialmente teniendo en cuenta que, los niveles inadecuados de AF son un factor de riesgo significativo de ictus recurrente y que el tiempo sentado es un factor de riesgo independiente de mortalidad relacionada con enfermedades cardiovasculares [50]. Por tanto, es una prioridad influir sobre los valores de AF para prevenir recidivas [76,78], siguiendo las recomendaciones de las actuales guías clinicas de rehabilitación [79,80] para maximizar la salud, el bienestar y la calidad de vida en personas supervivientes de un ictus [81].

1.3. Actividad física versus ejercicio físico

1.3.1. Descripción de la terminología

La AF es definida por la OMS como *"Cualquier movimiento corporal producido por los músculos esqueléticos que da lugar a un gasto energético que puede medirse en kilocalorías (Kcal) y puede clasificarse como ocupacional, deportiva, de fitness, doméstica o de otro tipo"* [52]. Esto incluye todo movimiento durante el tiempo de ocio, para desplazarse hacia y desde los lugares, o como parte del trabajo y las tareas domésticas de una persona [52]. La AF puede implicar diferentes intensidades, como AF ligera, moderada y vigorosa [52]. Asimismo, el ejercicio físico se definió por Caspersen et al. en 1985 [49] como *"Un subconjunto de AF planificada, estructurada y repetitiva con el objetivo final o intermedio de mejorar o mantener la forma física"*.

El dominio de AF incluye las subvariables mostradas en la tabla 1 según el reciente consenso de expertos de Fini et al. (2023) [82].

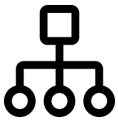
DOMINIOS DE ACTIVIDAD FÍSICA	SUBVARIABLES IDENTIFICADAS POR LOS INVESTIGADORES
Frecuencia de Actividad Física 	Número de pasos diario.
	Número de bloques de sedentarismo de más de 30 minutos al día.
	Número de bloques de actividad (caminar, transferencias, escaleras) al día.
Intensidad y duración 	Tiempo diario destinado a una combinación de actividad física moderada y vigorosa.
	Tiempo diario destinado a actividad física ligera.
	Tiempo semanal destinado a una combinación de actividad física moderada y vigorosa.
Intensidad 	Frecuencia cardiaca.
	Gasto energético- *Metabolic Equivalents of Task*
	Bloques de cadencia de pasos.
Duración 	Tiempo total destinado a conducta sedentaria (minutos al día).
	Minutos semanales habituales de actividad física.
	Minutos de ejercicios estructurados de cualquier intensidad (minutos al día).
Categoría 	Intensidad y duración de la actividad física.
	Frecuencia de actividad física.
	Duración de actividad física.
	Intensidad de actividad física.

Tabla 1. Dominios de la actividad física según el consenso de expertos de 2023. *Información adaptada de Fini NA, Simpson D, Moore SA, Mahendran N, Eng JJ, Borschmann K, Moulaee Conradsson D, Chastin S, Churilov L, English C. How should we measure physical activity after stroke? An international consensus. Int J Stroke. 2023* [82].

Por otro lado, la inactividad física se define por la OMS como *"Un nivel de AF insuficiente para cumplir las recomendaciones actuales establecidas por la OMS"* [52], definición respaldada por *The American Heart Association Council* [83]. Por otro lado, el comportamiento sedentario se define como *"Cualquier comportamiento durante la vigilia caracterizado por un gasto energético menor o igual a 1,5 Metabolic Equivalents of Task (METs), mientras se está sentado, reclinado o tumbado"* [53,84,85]. Este nivel de inactividad implica el incumplimiento de las recomendaciones de la OMS descritas Bull et al. (2020) [52] sobre la realización de AF de forma regular. Si este comportamiento sedentario se mantiene a lo largo del día o de la semana mientras se está despierto, puede clasificarse como un patrón de comportamiento sedentario [86].

En la figura 2 se exponen las relaciones entre el número de METs, la intensidad de la actividad y ejemplos de AF y de la vida cotidiana.

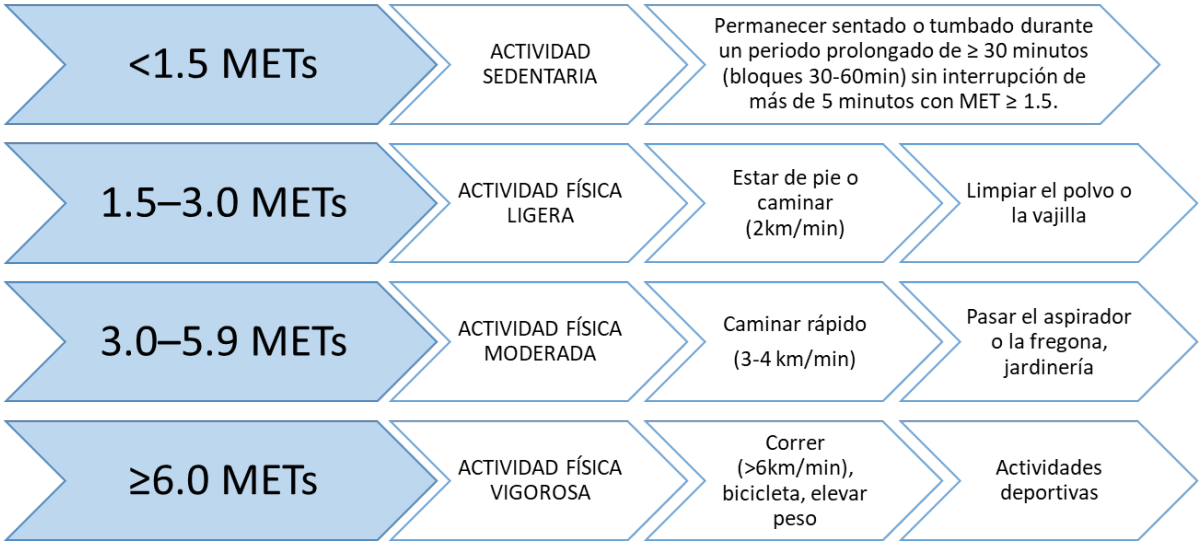


Figura 2. *Relación entre el número de Metabolic Equivalents of Task, la intensidad de la actividad y ejemplos de actividades físicas y de la vida cotidiana.* METs: *Metabolic Equivalents of Task*.

Tanto los METs como el gasto calórico medido en Kcal quemadas por minuto (Kcal/min) son subvariables de la AF que pueden ser calculadas a través de las siguientes fórmulas:

1MET= 3.5 mililitros oxígeno consumido x 1 kilogramo (peso) x 1 minuto (tiempo)

$$1\ \text{Kcal (calorías quemadas)} = \frac{\text{METs x 3.5 x kg (peso)}}{200}$$

1.3.2. Recomendaciones de la Organización Mundial de la Salud sobre la actividad física

La OMS se ha comprometido a reducir el riesgo y la mortalidad asociados a enfermedades no transmisibles como el ictus, siendo una prioridad la realización de AF de forma regular [56]. Es por ello que, uno de los objetivos clave dentro de *The European Stroke Action Plan* [33], iniciativa europea propuesta por *The European Stroke Organisation* y *The Stroke Alliance for Europe* es conseguir en 2030 incrementar el nivel de AF en los supervivientes de un ictus según Norrving et al. (2018) [33]. Se trata del mayor proyecto

sobre el ictus jamás emprendido en Europa, que establece objetivos para mejorar la atención al ictus en todo el continente hasta 2030. Asimismo, *The European Stroke Action Plan* 2018–2030 [33] complementa *The World Health Organization Global Action Plan on noncommunicable diseases* 2013–2020, *The World Health Organization -Europe noncommunicable diseases Action Plan* y *The Sustainable Development Goals* de 2015 a 2030 [33,87] (*Figura 3*).



Figura 3. *Objetivos establecidos por la Organización Mundial de la Salud. Información extraída de* https://www.un.org/sustainabledevelopment/es/2015/09/la-asamblea-general-adopta-la-agenda-2030-para-el-desarrollo-sostenible/

En este sentido, los beneficios para la salud de la AF están bien establecidos, y la OMS recomienda que todos los adultos realicen 150-300 minutos de AF de intensidad moderada o 75-150 minutos de AF de intensidad vigorosa cada semana o una combinación de ambas (AFMV) [52,88]. Estas recomendaciones también se aplican a los adultos mayores y a los adultos con enfermedades no transmisibles [52]. Concretamente, estas recomendaciones implican realizar un gasto de 1.000 Kcal/semana durante la realización de AF[89], alcanzar 10.000 pasos al día [90] o generar un gasto de 600-1200 METs/semana[91]. Sin embargo, este objetivo puede ser inalcanzable para algunas poblaciones, como los adultos mayores y las personas con secuelas de enfermedades como el ictus [85] (*Figura 4*).



Figura 4. *Recomendaciones de actividad física según la Organización Mundial de la Salud para personas adultas con discapacidad. Información adaptada de Asamblea Mundial de la Salud (2018). Actividad física para la salud: más personas activas para un mundo más sano: proyecto de plan de acción mundial sobre actividad física 2018-2030: informe del director General (No. A71/18). Organización Mundial de la Salud* [92].

Basado en el derecho a la rehabilitación amparada por "Los Derechos de las Personas con Discapacidad" y conociendo que se estima que 1 de cada 3 personas necesitará rehabilitación debido una patología entre las que se encuentra el ictus según indica Cierza et al. (2021) [43]. El objetivo de *The European Stroke Action Plan* [33], es garantizar que al menos el 90% de la población con ictus tenga acceso a programas de acondicionamiento físico siguiendo las directrices de la OMS a través de *"Rehabilitación 2030"* para alcanzar dicho objetivo descrito por Norrving et al. (2018) [33].

1.3.3. Nivel de actividad física en los supervivientes de un ictus

La mayoría de los supervivientes de un ictus son inactivos [85,93,94], presentando de forma generalizada una conducta sedentaria durante todas las fases de la recuperación [53], especialmente durante la tarde y la noche según afirma English et al. (2022) [95]. En concreto, alrededor del 70% de los supervivientes de un ictus no realizan la AF mínima posteriormente a su rehabilitación [96,97], aproximadamente el 40% reportan ser inactivos físicamente un año tras el ictus [98] y sólo el 17% sigue las recomendaciones de la OMS en cuanto a la realización de AF de forma regular [96]. Este porcentaje progresivamente va disminuyendo conforme pasan los años desde el ictus [85]. Los bajos niveles de AF son un

problema no sólo para los supervivientes de un ictus con un alto nivel de discapacidad, sino también para los que vuelven a caminar de forma independiente [99-102]. En concreto, el 75% de aquellos que presentan una alta capacidad funcional, pasan sentados la mayoría del tiempo que están despiertos [94].

Del total de los supervivientes de un ictus, entre el 65-85% [103], tienen secuelas leves que les permiten ser independientes en la marcha [104]. Estos realizan una media de 4.355 pasos al día [97], dato por debajo de la media recomendada para personas con discapacidad que se sitúa en 6.500-8.500 pasos al día [33], siendo la media 6.000-7.000 pasos al día en los adultos sanos [105]. Esta situación, les acaba ocasionando un progresivo desacondicionamiento físico [56]. Además, el número medio de horas de sueño es mayor en comparación con la población sana, lo que se asocia con mayor morbilidad y mortalidad cardiovascular [106]. Estos datos corresponden principalmente a estudios realizados en Europa, Australia, Canadá y Estados Unidos [53,85,93-95,101,107-109]; sin embargo, no existe información sólida sobre la conducta de las personas supervivientes de un ictus en España [85,110].

Un estudio cualitativo de Bailey et al. (2021) [111] reveló una preferencia en cuanto a la realización de ejercicio físico y la elección de actividades por las personas supervivientes de un ictus, pudiendo deberse a factores individuales como el nivel de capacidad, oportunidad o motivación, según Fitzsimons et al. (2022) [112]. Pero las razones relacionadas con este comportamiento sedentario son muy complejas, implicando relaciones multifactoriales hasta ahora poco estudiadas [112-116]. Entre los factores descritos por la literatura disponible [112,117-120], destacan los factores clínicos entre los que se encuentran los años transcurridos desde el ictus [117], la gravedad inicial del ictus [56,94,108], el tipo de hemiparesia, el nivel cognitivo [94,121,122], una mejor resistencia a la fatiga [123] y la velocidad de la marcha [94,120-122], que les hacen reducir su participación en la AF aeróbica [73]. Particularmente, el miedo a las caídas se asocia a un estilo de vida sedentario [124,125], llegando a reducir los supervivientes un 20% las actividades que implican estar de pie o caminar [126]. Por otro lado, Hasset et al. (2020) [93] destacan entre los factores sociodemográficos, el lugar de residencia y las características de la comunidad, y el apoyo social [127]. Y entre los factores psicosociales, señalan la ansiedad, la depresión y la autoeficacia [115,128]. Igualmente, importantes son la intensidad y la frecuencia del tratamiento de rehabilitación [127,129,130]. Pero, se ha observado que aquellos que se encuentran hospitalizados en centros de rehabilitación son más sedentarios [127,131]. Sin embargo, Hasset et al. (2020) [93] afirma que los que viven en la comunidad siguen sin

alcanzar un nivel saludable de AF. A pesar de todas estas barreras, el 84% de las personas expresan interés en hacer ejercicio después de un ictus [132], lo cual deja una puerta abierta a un diseño de intervención que consideren estas relaciones multifactoriales y sean capaces de individualizar sus planes de tratamiento según indica Egan et al. (2024) [133].

1.3.4. Beneficios de la realización regular de actividad física

Se sabe que la AF tiene grandes beneficios en personas sanas, existiendo una relación dosis-respuesta entre el ejercicio y riesgo de sufrir un ictus [134,135], llegando a reducir este riesgo un 25% [54,136] contribuyendo a la prevención primaria [57]. En personas supervivientes de un ictus, aunque las secuelas que presentan son inevitables, su estilo de vida sedentario es modificable [102]. En este sentido, no alcanzar el nivel de AF recomendado por la OMS es especialmente perjudicial para estas personas [85]. Concretamente, la inactividad física se asocia con un aumento del 20-30% del riesgo de mortalidad [46]. Sin embargo, la realización regular de AF tiene un efecto preventivo llegando a evitar en un 80% de la recurrencia del ictus y reduciendo la mortalidad prematura [33]. Asimismo, se ha demostrado que un estilo de vida activo, basado en la realización regular de AF contribuye al control de los factores de riesgo modificables de una recidiva [55,73-77,137].

Cabe destacar que Gunnes et al. (2019) [138] indicó que la realización regular de AF contribuye al proceso de recuperación de los supervivientes de un ictus, reduciendo las secuelas a largo plazo. Además, tiene un efecto positivo sobre la neuroplasticidad [139], generando un impacto sobre la promoción de la recuperación funcional [140,141], la capacidad funcional [59], la fatiga, el equilibrio [140], las funciones cognitivas y la dependencia de productos de apoyo (p. ej., férulas o bastones) o de terceras personas durante la marcha [142]. Todo este efecto neuroplástico, reduce la discapacidad e incrementa la independencia [56,141,143,144], aumenta la participación social, contribuyendo a mejorar la calidad de vida [59,60,145]. Por lo tanto, los beneficios de la AF son relevantes en la prevención primaria mitigando los factores de riesgo cerebrovasculares [46,52], así como en la prevención secundaria y terciaria en el tratamiento de las secuelas del ictus según afirma Keindorfer et al. (2021) [71].

1.4. ¿Qué se entiende por participación?

1.4.1. Descripción de la terminología

La Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud (CIF) definió la participación como *"La implicación de una persona en situaciones vitales, lo que supone una interacción entre el estado de salud del individuo y factores contextuales (es decir, factores ambientales y personales)"* [146-148]. Concretamente, la CIF agrupó en una única lista de 9 elementos los dominios de actividades y participación, siendo estos: Aprendizaje y aplicación de conocimientos, Tareas y demandas generales, Comunicación, Movilidad, Autocuidado, Vida doméstica, Interacciones y relaciones interpersonales, Principales áreas de la vida y Vida comunitaria, social y cívica. Pero la CIF también contempló especificar entre actividad y participación de tal manera que los dominios D1-D4 hacen referencia a la actividad y los dominios D5-D9 a la participación [149] (*Tabla 2*).

DOMINIOS			
PARTICIPACIÓN	ACTIVIDAD	**D1**	Aprendizaje y aplicación de conocimientos
		D2	Tareas y demandas generales
		D3	Comunicación
		D4	Movilidad
	PARTICIPACIÓN	**D5**	Autocuidado
		D6	Vida doméstica
		D7	Interacciones y relaciones interpersonales
		D8	Áreas principales de la vida
		D9	Vida comunitaria, cívica y social

Tabla 2. *Dominios de actividad y participación según la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud. Información adaptada de World Health Organization. (2001). Clasificación internacional del funcionamiento de la discapacidad y de la salud: CIF. Organización Mundial de la Salud* [150].

Sin embargo, la participación es un concepto muy complejo que implica no sólo la realización y rendimiento sino también la experiencia subjetiva, el significado de la actividad, la autonomía y la autodeterminación [146] entre otros aspectos. La participación consiste en la implicación activa de una persona en la realización de las actividades de la vida diaria, en encontrarles un propósito y un sentido [151]. Es una interacción persona-

tarea-entorno que cambia a lo largo de la vida y responde a las exigencias del entorno y de las tareas [152]. Así mismo, la participación comprende las actividades significativas realizadas por los individuos en su entorno real (p. ej., la familia o la comunidad) que ocupan su tiempo y que dan sentido y propósito a su vida [147]. De este modo, la participación aborda el equilibrio percibido entre estas actividades y la satisfacción que generan en la persona tanto si las realiza como si no, y la relación con los hábitos y desempeño de roles según aparece descrito por Roley et al. (2020) [153].

Es por ello por lo que *The American Occupational Therapy Association* puntualiza la diferenciación entre los términos participación, actividad y ocupación. En este sentido, define participación como *"Implicación en una situación vital"* [154], las actividades como *"Acciones diseñadas y seleccionadas para apoyar el desarrollo de habilidades y patrones de actuación que mejoren el compromiso ocupacional"* y la ocupación como *"Actividades cotidianas personalizadas que las personas realizan como individuos, en familia y con la comunidad para ocupar el tiempo y dar sentido y propósito a la vida. Las ocupaciones pueden implicar la ejecución de múltiples actividades para su realización y pueden dar lugar a diversos resultados. Las ocupaciones se clasifican en actividades de la vida diaria, actividades instrumentales de la vida diaria, gestión de la salud, descanso y sueño, educación, trabajo, juego, ocio y participación social"* [153] (*Figura 5*). Por lo tanto, el término de ocupación implica un compromiso personalizado y significativo en los acontecimientos de la vida diaria por parte de una persona específica. Por el contrario, el término actividad hace referencia a una forma de acción que es objetiva y no está relacionada con el compromiso o el contexto de una persona específica [155]. Desde este punto de vista, las ocupaciones se producen a lo largo del paso del tiempo en diferentes contextos y se ven influidas por la interacción entre los patrones de desempeño y los factores de la persona (*Tabla 3*). Asimismo, las ocupaciones tienen un propósito, un significado y una utilidad percibida por la persona [156].

Ocupaciones	Contexto	Patrones de desempeño	Habilidades de desempeño	Factores de la persona
Actividades de la vida diaria Actividades instrumentales de la vida diaria Gestión de la salud Descanso y sueño Educación Trabajo Juego Ocio Participación social	Factores del entorno Factores personales	Hábitos Rutinas Roles Rituales	Habilidades motoras Habilidades de procesamiento Habilidades de interacción social	Valores, creencias y espiritualidad Funciones corporales Estructuras corporales

Tabla 3. *Dominios de la terapia ocupacional según The American Occupational Therapy Association. Información adaptada de Occupational Therapy Practice Framework: Domain and Process (4th ed.; AOTA, 2020)* [153] .

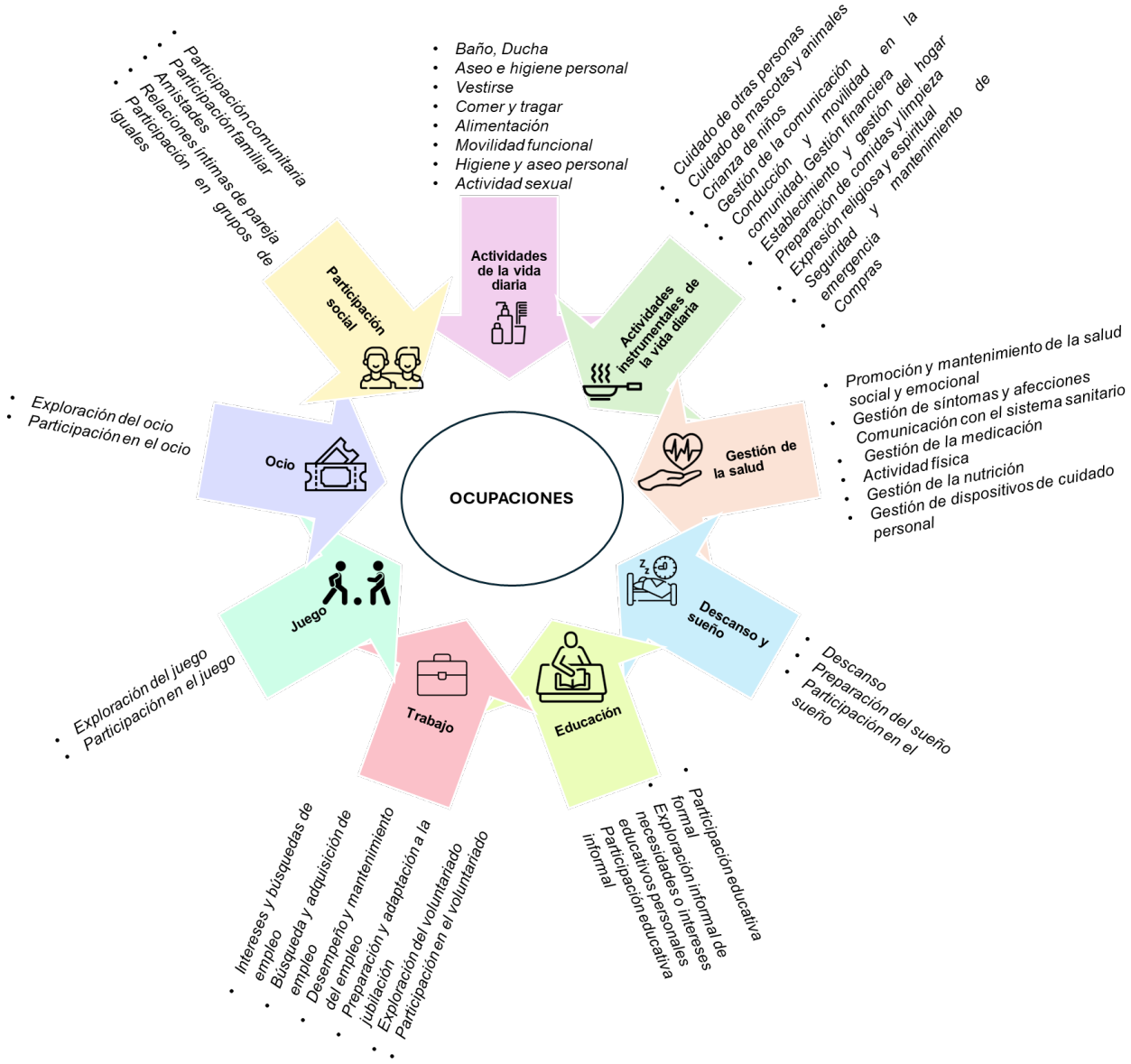


Figura 5. *Clasificación de las ocupaciones según The American Occupational Therapy Association. Información adaptada de Occupational Therapy Practice Framework: Domain and Process (4th ed.; AOTA, 2020)* [153].

1.4.2. Retorno a la participación después de un ictus

La participación es esencial para el bienestar y la calidad de vida de los supervivientes de un ictus [157,158]. Por lo tanto, alcanzar el máximo nivel de participación en las actividades en el entorno real es el objetivo final de la neurorehabilitación [159], especialmente de la Terapia Ocupacional [160] propósito también respaldado tanto por la OMS [148,161] como la CIF [15,19]. Cabe destacar que la gran mayoría de los supervivientes de un ictus presentan restricciones en la participación, especialmente en las actividades sociales, de ocio [13,162,163] , actividades laborales [164,165] y limpieza del hogar [15], a pesar de contar con elementos facilitadores como tener una red social extensa, conducir [13] o ser independiente en la marcha [13]. Estas restricciones en la participación [15,19] son evidentes incluso después de varios años desde el ictus [19]. Impactan sobre la satisfacción [166], pudiendo conducir a un desequilibrio ocupacional [167,168], un incremento de la dependencia, que genera un impacto familiar [169], y gasto sanitario y socioeconómico [34]. Estos problemas podrían reducirse con intervenciones centradas en incrementar la independencia y el retorno a la participación en actividades cotidianas [170]. En este sentido, según Engel-Yeger et al. (2018) [171] se desconocen las relaciones multifactoriales que implican un menor impacto del ictus sobre la participación comunitaria a corto o largo plazo. Entre los múltiples factores [15,18,99,117] descritos por la literatura se encuentran: los factores personales como la edad, actitud de la persona y aceptación de la nueva situación [171]; factores clínicos como las secuelas relacionadas con el ictus [13,19] y comorbilidades [17,172] como el deterioro cognitivo y los estados depresivos [173]; el entorno físico, el apoyo familiar [17,172] y social; así como el acceso a los recursos disponibles tanto sanitarios como sociales [17,19,172]. Pero las restricciones en la participación pueden deberse a otros factores hasta ahora menos analizados, como los factores ambientales relacionados con el clima y las horas de luz [121] y el impacto de los diferentes modelos asistenciales [9,174-176], la resiliencia [163], el entorno social, familiar y la influencia del cuidador principal [128,177]. En este sentido, es necesario tener en cuenta que un alto porcentaje de supervivientes de un ictus reside en su propio domicilio gracias al soporte familiar o de personal contratado, sin datos concluyentes sobre la influencia natural que puede generar sobre el retorno o no a la independencia en la participación como indica Hall et al. (2020) [128].

Es por tanto, crucial conocer las relaciones multifactoriales y la historia ocupacional, para entender las prioridades individuales y el estilo de vida de los supervivientes de un ictus que les llevan a mantener, abandonar o iniciar actividades a

largo plazo como apunta Norlander et al. (2021) [110]. Es necesario tener en cuenta el tiempo transcurrido desde el ictus, ya que se ha determinado que el retorno a la participación puede requerir una media de 4 años según la revisión sistemática de Wesselhoff et al. (2018) [99] necesitando entre 7-8 años para aceptar el nivel de participación alcanzado según señala Törnbom et al. (2019) [178].

En este sentido, de lo poco que se conoce de los supervivientes de un ictus españoles, se ha observado que las actividades más deterioradas son el trabajo, la lectura de libros, el ocio y las actividades domésticas, siendo las personas con mayor participación, las que presentan mayor capacidad de independencia funcional [179].

Las recientes revisiones sistemáticas muestran que, las intervenciones posteriores al ictus no repercuten en la participación en la comunidad hasta varios años después del ictus [180].Siendo clave la identificación de las barreras y las relaciones multifactoriales [99], así como la información cuantitativa y cualitativa sobre el impacto de estos factores sobre la participación en estas personas [19,32,172,181]. En este sentido, resaltan que el éxito de la reintegración comunitaria en los supervivientes de un ictus depende de la realización de actividades significativas, la reducción de la dependencia de otras personas o familiares y el mantenimiento de relaciones sociales [180]. Estos factores se suman a la importancia de conocer las prioridades individuales y el rol e identidad ocupacional para comprender los motivos para iniciar, continuar o renunciar a la realización de actividades como muestra Norlander et al. (2021) [110].

1.5. Relación entre la actividad física y la participación

A pesar de que el estudio de English et al. (2014) [102] sugirió una relación entre la participación en la vida diaria y la intensidad de la AF y una reciente investigación de Espernberger et al. (2021) [115] encontró una relación entre la participación en actividades de la vida diaria y los niveles de AF, es necesario continuar profundizando sobre la naturaliza de dichas relaciones. Ahora ahora , los datos indican que existe una asociación entre los niveles de AF y el retorno a la participación y adaptación a la vida después del ictus [140]. Del mismo modo que, un bajo nivel de AF posterior al ictus se asocia a un mayor grado de dependencia en la realización de actividades cotidianas, y por lo tanto, a un incremento del gasto sanitario debido a la necesidad de recursos según Rochmah et al. (2021) [34].

A pesar de que las intervenciones multifactoriales sobre hábitos de vida saludables demostraron tener un mayor efecto [182], gran parte de los estudios recopilados en revisiones sistemáticas previas se centraban en el nivel de AF [97] sin tener en cuenta su relación con el retorno a la participación, el gasto energético implicado [111,183], o la adherencia a continuar con las pautas indicadas tras la rehabilitación traducida en hábitos y perfiles conductuales [73,184]. A pesar de que se presupone que la adopción de un estilo de vida saludable, basado en la realización de AF y participación activa en las actividades cotidianas puede contribuir significativamente al bienestar y la salud generales después de un ictus [32,33], hasta ahora no hay ninguna revisión sistemática que recopile la evidencia científica disponible hasta la fecha o estudios transversales con amplias muestras poblacionales que puedan reforzar la correlación entre los niveles de AF y participación en personas supervivientes de un ictus.

1.6. Herramientas de resultado de la actividad física y la participación

1.6.1. Herramientas de valoración de la actividad física

Los niveles de AF pueden medirse mediante cuestionarios autoinformados, herramientas de evaluación objetivas (p. ej., podómetros, acelerómetros o dispositivos de monitorización de la AF) [185,186], o métodos de observación directa. A continuación, se abordarán tanto las herramientas de valoración a través de cuestionarios autoinformados como a través de dispositivos que aportan datos objetivos.

1.6.1.1. Cuestionarios autoinformados

En cuanto a los cuestionarios autoinformados en adultos, existe un gran abanico de opciones de bajo coste y fácil administración [187-189], que frecuentemente se utilizan en población adulta sin patología [59,85,144], a pesar de desconocer en su gran mayoría las propiedades psicométricas [188,189] en población superviviente de un ictus.

A pesar de que una revisión sistemática indica que, hay una baja-moderada correlación entre los valores aportados sobre la AF evaluada subjetivamente y el registro a través de dispositivos objetivos [187], los cuestionarios autoinformados podrían ser una excelente opción en el ámbito clínico en el caso de mostrar buenas propiedades

psicométricas. Fini et al (2015) [190] hallaron una alta fiabilidad test-retest y capacidad de detectar umbrales bajos de actividad.

Tanto *The Frenchay Activities Index* como *The Human Activity Profile* son las herramientas recomendadas para evaluar la AF en la población de superviviente de un ictus, demostrando buenas propiedades psicométricas [191]. Sin embargo, mientras que el *The Frenchay Activities Index* evalúa la frecuencia, *The Human Activity Profile* evalúa la intensidad; pero ninguna de ellas proporciona información para evaluar el cumplimiento de las recomendaciones de la OMS (p. ej., minutos de actividad o intensidad). Es por ello por lo que el reciente consenso de Fini et al. (2023) [82], recomienda utilizar como cuestionarios autoinformados *The International Physical Activity Questionnaire* (IPAQ), *Physical Activity Scale for the Elderly* o *Physician-based Assessment* and *Counseling for Exercise score*. En este sentido, el IPAQ es una herramienta comúnmente utilizada para evaluar los niveles de AF en adultos sin patologías [188,192,193]. Tanto IPAQ-*Sort Form* (IPAQ-SF) como IPAQ-*Long Form* tienen propiedades psicométricas equivalentes [194], y al cubrir las dimensiones de intensidad, frecuencia, duración y gasto energético de la AF, facilitan conocer si se cumplen las recomendaciones de la OMS (*Figura 4*). IPAQ-*Long Form* tiene una fuerte correlación con el acelerómetro ActiGraph GT3X+ [195] y se considera una herramienta útil para el cribado de los supervivientes de un ictus que permanecen crónicamente inactivos requiriendo intervenciones específicas para promover hábitos saludables según Ruescas-Nicolau et al. (2021) [195]. Aunque una revisión sistemática sobre IPAQ-SF en diferentes poblaciones (sin incluir ictus) mostró una sobreestimación de la cantidad de AF en comparación con los dispositivos objetivos (p. ej., acelerómetros) [196], hasta la fecha se desconocen sus propiedades psicométricas en supervivientes de ictus [145]. Es por ello por lo que, IPAQ-SF podría considerarse una herramienta clínicamente útil y óptima para ser utilizada en la población de supervivientes de un ictus [189,191] si demuestra que dispone de buenas propiedades psicométricas cuando se administra en personas supervivientes de un ictus.

1.6.1.2. Dispositivos de monitorización

Los dispositivos de monitorización permiten recoger información objetiva sobre todas las subvariables de la AF como el número de pasos diario o rítmo de paso según Peters et al. (2021) [197]. Pero la mayoría de estos dispositivos aún requieren de un proceso de validación para su uso en supervivientes de un ictus [198,199]. Según una revisión

sistemática de 2018, las cinco marcas más utilizadas en los proyectos de investigación son Fitbit, Garmin, Misfit, Apple y Polar, siendo Fitbit la que destaca [198]. Mientras que Fini et al. (2017) [85] indica que los dispositivos mas utilizados en investigación son Actigraph GT3X + y el Activ-PAL, la población sana suele adquirir para su vida cotidiana Fitbit, Apple Watch y Garmin VivoSmart HR+.

La revisión sistemática de Fini et al. (2015) [190], que investigó las propiedades de las herramientas de valoración de la AF específicamente para personas supervivientes de un ictus, e indicó que sólo 5 dispositivos fueron capaces de detectar mejoras en el nivel de actividad en los estudios longitudinales. Concretamente estos dispositivos fueron: Activ-PAL, el monitor de actividad de 3 acelerómetros, PAL 2, SAM y el Sensewear Pro3 [190].

Cabe destacar que, una revisión sistemática realizada en 2015 por Evenson et al. [199] indicó que ciertos modelos de Fitbit tienen una alta fiabilidad para cuantificar los pasos, el gasto de energía y monitorizar el sueño en personas sanas [200-203] y puede ser adecuada en supervivientes de un ictus [204,205] para monitorizar los niveles de AF al mismo tiempo que promueve la realización diaria de AF [206]. No obstante, su fiabilidad en estas personas debe ser demostrada, ya que el algoritmo de estos dispositivos fue diseñado para su uso en la población general [206]. Asimismo, tanto para el uso clínico, como de investigación estos dispositivos deben ser económicos, fáciles de usar, y llevar, discretos, ligeros, cómodos y tolerables para los supervivientes de un ictus. Además, debieran de disponer de una batería de larga duración, ser impermeables y con capacidad de transmitir datos de forma inalámbrica, así como capaces de proporcionar datos o información que sean significativos para modificar conductas sedentarias en los supervivientes de un ictus [207]. Pero hasta la fecha ningún dispositivo cumple todos estos criterios para la aplicación clínica [190]. En este sentido, el reciente consenso de expertos de 2023 recomendó para el registro de la AF en investigación y la práctica clínica diversos dispositivos en función de la subvariable de AF que se quiere valorar, tal y como se indica en la tabla 4.

DOMINIOS DE LA ACTIVIDAD FÍSICA	DISPOSITIVOS RECOMENDADOS PARA UTILIZAR EN INVESTIGACIÓN	DOMINIOS DE LA ACTIVIDAD FÍSICA	DISPOSITIVOS RECOMENDADOS PARA UTILIZAR EN LA PRÁCTICA CLÍNICA	CUESTIONARIOS RECOMENDADOS
Intensidad de actividad física (p. ej., Gasto energético)	Actigrap Actical Activ8	Frecuencia de la actividad física	Fitbit (llevado en tobillo)	International Physical Activity Questionnaire Physical Activity Scale for the Elderly Physician-based Assessment and Counseling for Exercise score Stroke Physical Activity Questionnaire.
Duración de la actividad física (p. ej., Tiempo destinado en posiciones)	ActivPAL	Intensidad de la actividad física		
Frecuencia de la actividad física (p. ej., Número de pasos)	Step Activity Monitor	Duración de la actividad física		

Tabla 4. *Dispositivos para registrar actividad física en supervivientes de un ictus recomendado por el consenso de expertos de 2023. Información adaptada de Fini NA, Simpson D, Moore SA, Mahendran N, Eng JJ, Borschmann K, Moulaee Conradsson D, Chastin S, Churilov L, English C. How should we measure physical activity after stroke? An international consensus. Int J Stroke. 2023* [82].

Por otro lado, con relación al procedimiento de registro a través de estos dispositivos de monitorización, Fini et al. (2019) [208] determinó que es necesario disponer al menos de 3 días de registro durante un mínimo de 14 horas al día, para poder realizar un seguimiento preciso y reducir sesgos según Fini et. Al (2022) [209]. Sin embargo, Tinlin et al. (2018) [210] apuntó que si se requiere disponer de datos más sensibles para registrar la AF modera a vigorosa, se recomienda realizar una monitorización de al menos 7 días completos. Desde un punto de vista científico, la accesibilidad a la información aportada por estos sensores portátiles puede beneficiar la traslación de la investigación centrada en el laboratorio a la vida cotidiana pudiendo registrar la actividad de la persona en su contexto comunitario. Pero hasta ahora esta tecnología ha sido infrautilizada [85,197].

1.6.2. Herramientas de valoración de la participación

La participación en las diferentes áreas de la ocupación (*Figura 5*) ha sido un dominio especialmente abordado por la disciplina de Terapia Ocupacional y que desde 2001 fue incluido dentro del marco de la CIF [154]. Sin embargo, en España, las herramientas de valoración de la participación más utilizadas desde la Terapia Ocupacional recogen principalmente datos únicamente el nivel de desempeño en las actividades de la vida diaria [211]. Además, en el ámbito clínico se suelen administrar sin profundizar en sus propiedades psicométricas, como la validez de contenido y constructo, la validez para ser administrado en una población concreta, sensibilidad al cambio o su adaptación al contexto español según Prieto-Botella et al. (2022) [212]. No obstante, la revisión sistemática de Ezekiel et al. (2019) [17] indicó que, a pesar de existir diversas herramientas que pueden utilizarse para evaluar el impacto del ictus y los hábitos de vida, ninguna de ellas cubre los nueve dominios de participación identificados por la CIF o las subvariables de participación identificadas por los enfoques y marcos de trabajo de Terapia Ocupacional más relevantes [153,213,214] (*Tabla 3*) . Por lo tanto, la gran mayoría de las herramientas aportan información sesgada, al no abordar el dominio de participación en su totalidad, ignorando frecuentemente información sobre la experiencia subjetiva de la participación o la autonomía percibida [146,153]. Igualmente, la gran mayoría de las herramientas disponibles no permiten especificar en cuál de las actividades se ha producido la mejoría [81,215].

Entre las herramientas más utilizadas para valorar la participación en supervivientes de un ictus se encuentran *Life-Satisfaction Questionnaire-11* [216-219]*, The Reintegration to Normal Living Index* [220-222], *The Patient-Reported Outcome Measure Information System* [223], *The Occupational Gaps Questionnaire* [152,224-226], *Meaningful Activity Participation Assessment* [227] y *Canadian Occupational Performance Measure* [228]. Pero según Ezekiel et al. (2019) [17] todas ellas proporcionan información incompleta sobre el dominio de la participación, siendo recomendable utilizar más de una para disponer de una visión holística.

Entre las herramientas para valorar la participación bajo el marco de CIF [17] en supervivientes de un ictus [172] destacan *Stroke Impact Scale* (SIS) y *Assessment of Life Habits Scale* y el *Activity Card Sort* (ACS) [17]. Aunque ninguna de ellas incluye los nueve dominios de actividad y participación, ni los distintos dominios de participación del marco de la Terapia Ocupacional [153]. Por otro lado, entre las herramientas disponibles en

español, se encuentran *The Barthel Index* (BI) y el SIS, pero ambas de nuevo, proporcionan una información incompleta. Es necesario tener en cuenta que no aportan datos sobre el nivel de participación en las diferentes áreas de participación [153,229], restricción o dependencia en la participación, cambios en la participación como consecuencia de una enfermedad, satisfacción, o equilibrio en la participación e impacto en la calidad de vida [171,211]. En este sentido, a pesar de que SIS es una de las herramientas de valoración más frecuentemente utilizada para valorar el nivel de participación en supervivientes de un ictus [171], y recientemente recomendada por un consenso de expertos [215], Mulder et al. (2016) [232], creador de esta herramienta, indicó se creó para registrar la calidad de vida tras un ictus [230]. Así mismo, el BI sólo cubre el nivel de participación en la realización de las actividades básicas de la vida diaria, y su puntuación final no permite especificar en cuál de las actividades básicas se ha producido la mejoría [231]. Del mismo modo, la herramienta ACS, ha sido recomendada en diversas revisiones sistemáticas para los dominios de actividad y participación de la CIF en la población con ictus [211,232], pero sólo aporta información sobre el porcentaje de mantenimiento en la participación con relación al estilo de vida previo.

Por lo tanto, hasta la fecha, existe una ausencia de instrumentos de evaluación validados en población española con ictus que midan todas las dimensiones del dominio de participación [93,233,234], como el grado de desempeño ocupacional, satisfacción y equilibrio ocupacional a través de una entrevista cualitativa o el impacto percibido del ictus en las actividades [235] aportando una información incompleta sobre la participación [171]. Debido a esta situación, una revisión sistemática [17] expone la necesidad de disponer de herramientas de valoración, que demuestren adecuadas propiedades psicométricas y abarquen el dominio de participación [172,178].

1.7. Referencias

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CAPÍTULO 2. JUSTIFICACIÓN

Los supervivientes de un ictus presentan un amplio abanico de secuelas que impactan sobre su estilo de vida, reduciendo su nivel de AF y participación en las actividades de la vida cotidiana. A pesar de que se sabe que el proceso de reorganización del sistema nervioso central, debido a los diversos mecanismos de neuroplasticidad, tiene lugar incluso después de haber sufrido un ictus. Este proceso puede tender a alcanzar un proceso de estabilización o progresión más lenta pasados los primeros meses, si no se realizan intervenciones intensivas especialmente diseñadas para generar cambios.

Es por ello por lo que, en los últimos años se ha incrementado la investigación sobre el estilo de vida en los supervivientes de un ictus, focalizando el interés sobre su sedentarismo y el retorno a la participación. Pero no se ha prestado especial atención a la relación multidimensional entre ambas variables a pesar de que contribuyen a un estilo de vida saludable en estas personas. Sin embargo, hasta la actualidad no se dispone de una síntesis de información científica, sobre la relación entre los niveles de actividad física y participación, así como la influencia multidimensional de otros factores sobre el estilo de vida de las personas supervivientes de un ictus e información cualitativa que pueda complementar y enriquecer los datos objetivos recopilados para alcanzar una comprensión holística de la situación actual en España.

Asimismo, se desconoce si los resultados y conclusiones de los escasos estudios disponibles hasta la fecha, que han abordado las relaciones entre el nivel de actividad física y participación en actividades cotidianas, pueden ser extrapolables a la población española.

En cuanto a los supervivientes de un ictus que residen en España, no se disponen de datos actualizados que permitan entender las prioridades individuales y la historia ocupacional, para comprender por qué después de 6 meses de un ictus, las personas continúan, no retoman o exploran nuevas actividades. Disponer de esta información será relevante, para establecer un consenso sobre los factores clave sobre los que centrar las intervenciones en supervivientes de un ictus.

Por lo tanto, esta Tesis Doctoral ha focalizado su investigación en personas que tras 6 meses después del ictus han alcanzado un nivel de funcionalidad alto, principalmente debido a su independencia en la marcha, funciones cognitivas y

habilidades de comunicación preservadas. Pero se desconoce el estilo de vida de este subgrupo de supervivientes de un ictus, con mayor nivel funcional que residen en España. Estas personas no deberían presentar grandes limitaciones para realizar actividad física y retomar la participación en actividades cotidianas. Asimismo, alcanzar un estilo de vida similar al previo al ictus, potencialmente más saludable y alineado con las recomendaciones de la OMS.

Por otro lado, los datos aportados por revisiones sistemáticas previas y consensos de expertos sobre las carencias y necesidades de las herramientas de valoración disponibles para ser administradas en supervivientes de un ictus, han motivado la necesidad de elaborar los estudios de validación de las herramientas IPAQ-SF y versión española *The Satisfaction with Daily Occupations-Occupational Balance* (SDO-OB) para conocer si presentan propiedades psicométricas adecuadas en personas supervivientes de un ictus.

CAPÍTULO 3. HIPÓTESIS Y OBJETIVOS

3.1. Hipótesis

Considerando la información aportada en los capítulos 1 y 2, se hipotetiza que puede existir una relación entre las variables actividad física y participación en las personas supervivientes de un ictus, donde a pesar de presentar un alto nivel funcional se presupone que presentan bajos niveles de AF y dificultades para el retorno a la participación, habiendo una correlación entre ambas variables, así como una influencia multifactorial y vivencial hasta ahora no explorada. En este sentido se sospecha que las herramientas de valoración *IPAQ-SF* y *SDO-OB* poseen buenas propiedades psicométricas para abordar la complejidad de las variables actividad física y participación en supervivientes de un ictus y aportar datos sobre dicha situación.

3.2. Objetivo general

La presente Tesis Doctoral tiene por objetivo explorar multidimensionalmente el estilo de vida de las personas con alto nivel de funcionalidad que habían tenido un ictus al menos hace 6 meses, en relación con su nivel de actividad física y participación en la vida cotidiana.

En base a este objetivo general, se detallan a continuación los objetivos específicos y su relación con cada uno de los artículos que componen este compendio.

3.3. Objetivos específicos

I Describir e investigar la correlación y la trayectoria a lo largo del tiempo entre los niveles de AF y participación en la vida cotidiana de los supervivientes de un ictus.

II Evaluar las propiedades psicométricas (validez de contenido, constructo y apariencia, y la estabilidad test-retest) de la versión española de IPAQ-SF en supervivientes de ictus de hace más de 6 meses, capaces de caminar y que conservaban las capacidades cognitivas y de comunicación.

III Evaluar las propiedades psicométricas (consistencia interna, validez convergente, validez de grupo conocido, efectos suelo y techo, y fiabilidad test-retest) de la versión española de SDO-OB, cuando se utiliza en personas que han sufrido un ictus hace más de 6 meses.

IV Analizar la correlación entre la AF y la participación en los supervivientes españoles de ictus que caminan de manera independiente.

V Describir la experiencia de los supervivientes de ictus con alta capacidad funcional en España en relación con sus hábitos y preferencias de AF y ejercicio físico, explorando la influencia del entorno y del individuo para comprender sus razones para realizar y adherirse tanto a la AF como al ejercicio físico.

VI Conocer las vivencias durante el proceso de retorno a la participación y los factores que lo han condicionado en las personas que han tenido un ictus dentro del contexto sociocultural de España, y contexto vital en el que cada una de estas personas se encuentra tras el ictus.

CAPÍTULO 4. MATERIAL Y MÉTODOS

4.1.Diseños

La presente Tesis Doctoral incluye 8 publicaciones de las cuales dos son protocolos (*Anexo 4*) y seis estudios de investigación, que forman parte de un proyecto de investigación más amplio llamado Part&Sed-Stroke (*Figura 6*) aprobado en octubre de 2021 por el Comité de Ética de la Investigación de la Comunidad Autónoma de Aragón (PI21/333).



Figura 6. *Logo del Proyecto de investigación Part&Sed-Stroke.*

En este apartado se presentan, de manera resumida, los principales materiales y métodos utilizados en los estudios de investigación cuyo contenido se abarca en profundidad en cada uno de los artículos presentado en el apartado de resultados.

En primer lugar, se expone el diagrama de flujo en la figura 7 en relación al ***artículo 1*** de revisión sistemática con metaanálisis sobre la AF y la participación en supervivientes de un ictus. Posteriormente se muestra de forma sintetizada en la tabla 8 el contenido referente a material y métodos que se encuentra detallado en este artículo.

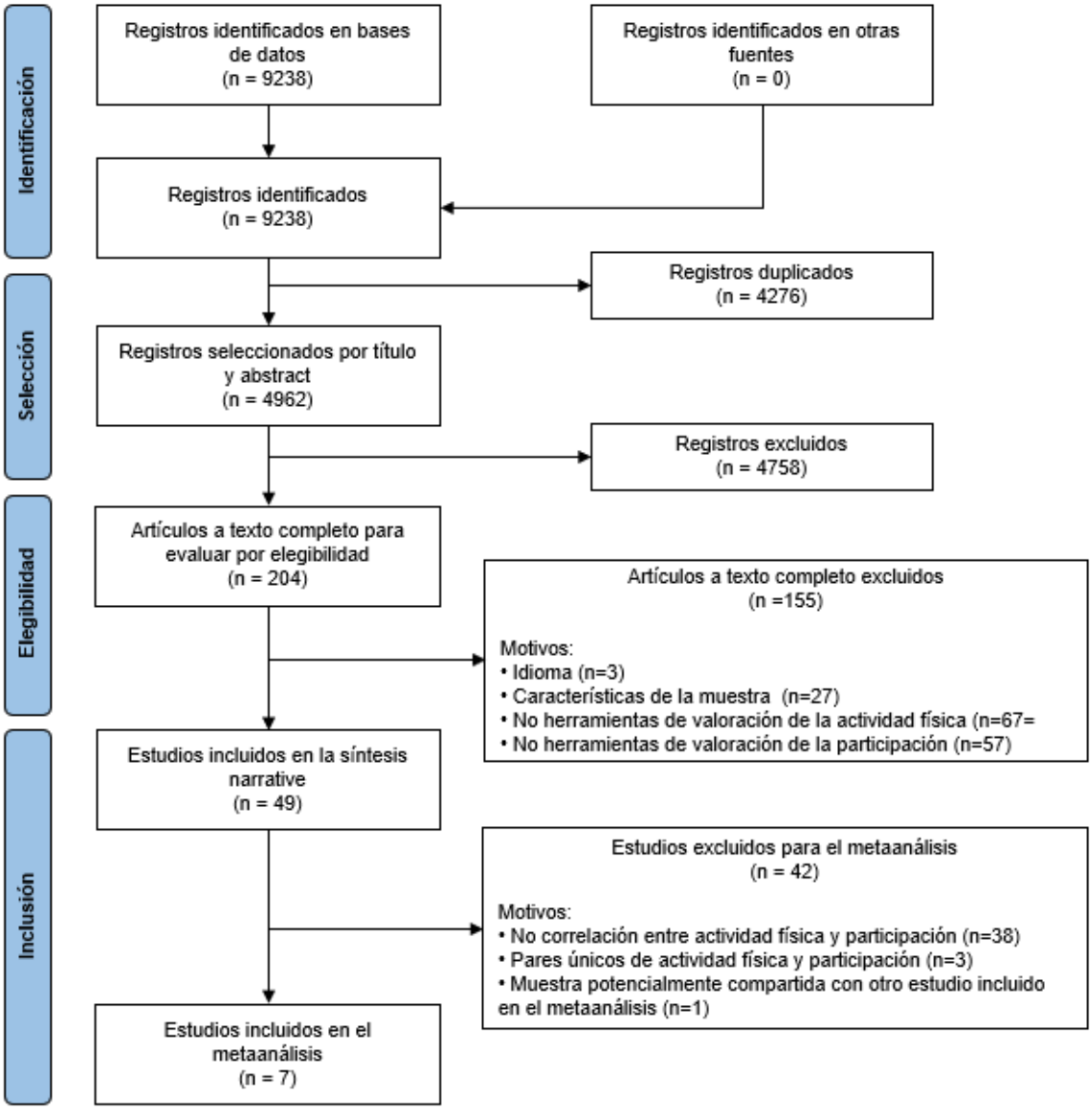


Figura 7*. Diagrama de flujo de la revisión sistemática con metaanálisis.*

A continuación, se muestra la temporalidad en la que se administraron las herramientas de valoración agrupadas en cuatro bloques en relación a los ***artículos 2, 3 y 4*** *(Figura 8).* Posteriormente, se mostrarán de forma agrupada los apartados de material y métodos de forma agrupada en relación al contenido de los ***artículos 2 y 3*** correspondientes a estudios de validación de las herramientas de valoración IPAQ-SF y SDO-OB respectivamente (*Tabla 9*) y al ***artículo 4*** relativo al estudio transversal para el análisis de correlaciones entre las variables AF y participación (*Tabla 9*).

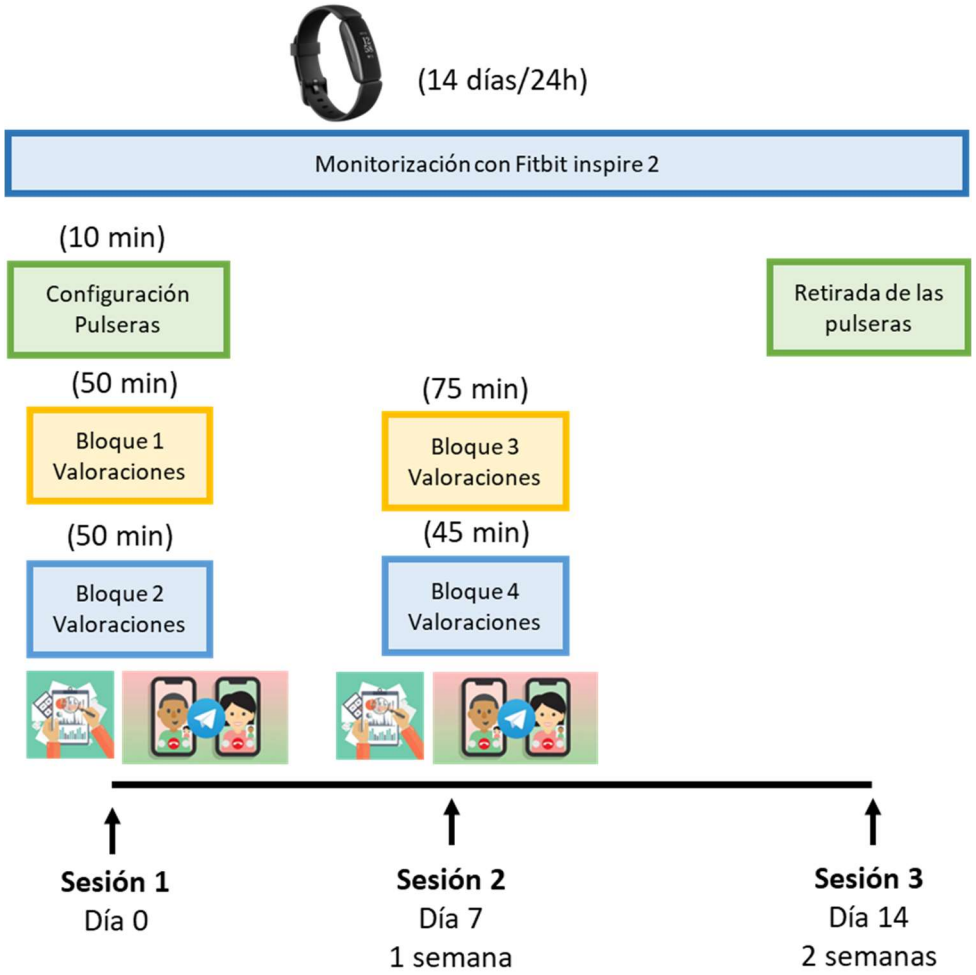


Figura 8. *Temporalidad de la administración de las herramientas de valoración agrupadas en cuatro bloques.*

Finalmente se abordarán los ***artículos 5 y 6*** en relación a los estudios cualitativos fenomenológicos centrados en conocer la experiencia vivida tras el ictus en relación a la AF y la participación respectivamente (*Tabla 10*).

Dentro del proceso metodológico de ambos estudios, se realizó un *bracketing* en 2 fases. Por un lado, siguiendo las indicaciones de Malterud [1], se describió la orientación y tipo de diseño, suposiciones previas del investigador y motivación que guió el desarrollo de la investigación (*Tabla 5*). Por otro lado, se planteó a 3 participantes preguntas abiertas para no condicionar ni guiar sus respuestas, favoreciendo el diálogo y empoderando al informante en la conversación para posteriormente elaborar las entrevistas semiestructuradas y posterior análisis de como indica la figura 9. Cada uno de los procesos aparecen detallados en profundidad en los artículos 5 y 6.

Contenidos del bracketing	Descripción
A. Orientación y tipo de diseño del estudio	Estudio cualitativo fenomenológico [2] siguiendo el marco de trabajo de Husserl's [3] , dirigido a describir la experiencia de las personas que han tenido un ictus en relación a su estilo de vida actual en relación a la realización de actividad física y actividades cotidianas.
B. Suposiciones previas del investigador	• Profesión: Terapeuta Ocupacional y Fisioterapeuta especializada en atención de personas con patología neurológica adultas. Personal docente investigador en el Grado de Fisioterapia y docente en cursos de postgrado. • Experiencia profesional previa: experiencia profesional como terapeuta ocupacional y fisioterapeuta en la asistencia clínica de personas con patología neurológica en diversos centros tanto públicos y privados como asociaciones. Durante 15 años ha atendido a diferentes personas supervivientes de un ictus en diferentes etapas posteriores al ictus (desde los primeros meses hasta pasados varios años desde el ictus) y en diferentes entornos (ingreso hospitalario, ambulatorio y domiciliario). La gran mayoría de las sesiones de rehabilitación han tenido una duración de unos 60 minutos durante varios días a la semana a lo largo de varios meses e incluso años en los cuales se ha establecido un fuerte vínculo con algunas personas supervivientes de un ictus que han traspasado el ámbito asistencia y dando lugar a un espacio de diálogo de gran confianza para abordar aspectos más personales. • Creencias: - Cada persona superviviente de un ictus vive el proceso de forma diferente y hay diversos factores que influyen en su proceso de recuperación e influyendo directamente en la intervención desde terapia ocupacional y fisioterapia (especialmente en entorno familiar y actitud de la persona). - Actualmente los modelos de rehabilitación dan poca importancia a estos factores y pasados 6 meses se centran en "mantener a la persona" sin explorar opciones de cambio. Los abordajes centrados en la función sensoriomotora no generan un impacto sobre las inquietudes que tiene la persona en su día a día. No se incluye de forma generalizada una educación para la salud donde la persona sea el motor principal. - En función del género la forma de afrontar la situación del ictus es muy diferente, especialmente los hombres supervivientes de un ictus adquieren el rol de paciente a pesar de incrementar su nivel funcional, pero las mujeres supervivientes de un ictus retoman sus roles con mayor rapidez y los cuidados suelen darse por un cuidador contratado y raramente es el marido.
C. Motivación para llevar a cabo la investigación.	Plasmar la experiencia de las personas supervivientes de un ictus desde su propia vivencia reflejando todos aquellos aspectos que en los diálogos del día a día en las sesiones de rehabilitación se comentan y raramente se contemplan en el ámbito científico pudiendo ser claves para generar un cambio en la atención a las personas supervivientes de un ictus. Dar a conocer las historias de personas supervivientes de un ictus, lo que necesitan para incrementar su independencia y felicidad.

Tabla 5. *Proceso de Bracketing*

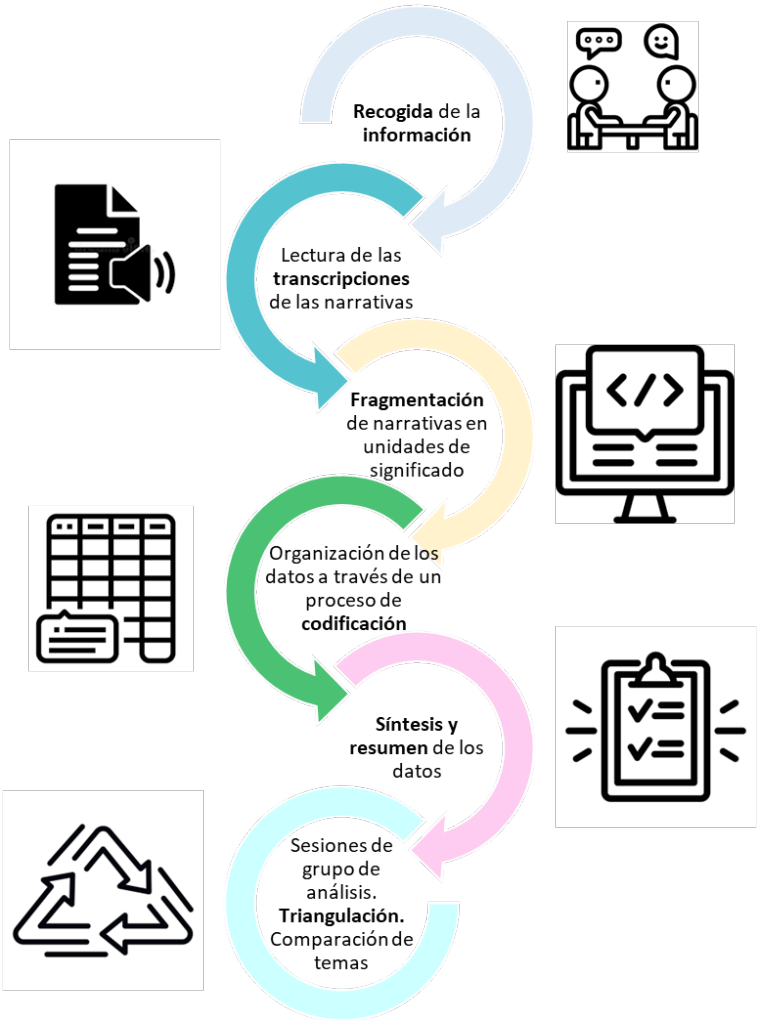


Figura 9. *Proceso de recogida y análisis de datos cualitativos.*

4.2.Participantes

Los **artículos 2, 3, 4, 5 y 6** forman parte del proyecto de investigación multicéntrico Part&Sed-Stroke. En este proyecto participan 20 centros de rehabilitación, clínicas y hospitales provenientes de 8 comunidades autónomas (*Figura 10)*. Además, en la administración de algunas de las herramientas de valoración han colaborado 30 profesionales sanitarios (19 fisioterapeutas, 11 terapeutas ocupacionales) (*Tabla 6*), a partir de ahora denominados profesionales colaboradores. Asimismo, 7 de estos profesionales colaboradores también han participado en algunos de los estudios piloto de este proyecto de investigación. En el reclutamiento de personas que cumplían los criterios de selección se ha alcanzado una muestra total de 140 participantes que residían en 27 ciudades diferentes. En los ***artículos 2, 3, 4, 5 y 6*** han participado la totalidad o parte de la muestra perteneciente al proyecto de investigación Part&Sed-Stroke.

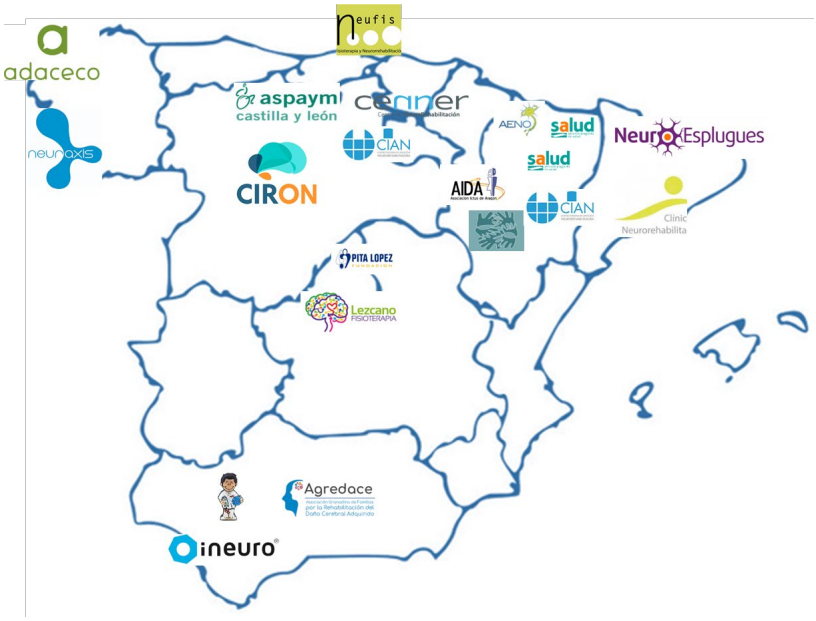


Figura 10. *Localización geográfica de los centros participantes en el proyecto de investigación Part&Sed-Stroke.*

CIUDAD	CENTRO COLABORADOR	PROFESIONALES COLABORADORES
A Coruña	**ADACECO**	Inés, Cortés Cabeza;Claudia Marín Marín;Rebeca, Yebra Vilarchao
Huesca	**AENO**	Ana, Conte Lamenca
Granada	**AGREDACE**	Diana Ruiz Ramos
Zaragoza	**AIDA**	Lilian, Le Roux;Sara, Beltrán Roche
Burgos	**ASPAYM**	Elena, Sanz Sanza
Pamplona	**CENNER**	Leyre, Leceaga Gaztambide
San Cugat del Vallés	**CENTRO NEUROREHABILITACIÓN**	Carina, Salgueiro
Valladolid	**CIRON**	Fernando, Cuesta Ruiz
Madrid	**FUNDACIÓN PITA LÓPEZ**	Javier, Harguindey
Pamplona	**GRUPO 5 CIAN PAMPLONA**	Andrea, Yerro Astrain
Zaragoza	**GRUPO 5 CIAN ZARAGOZA**	Enrique, Villa Berges
Huesca	**HOSPITAL PROVINCIAL SAGRADO CORAZÓN DE JESÚS**	Paz Cristina, Sánchez Lecina;Lourdes, Martín Gros;Paloma, Rodríguez Escudero
Huesca	**HOSPITAL UNIVERSITARIO SAN JORGE**	María Carmen, Grácia Sen;María Pilar, Pardo Sanz
Sevilla	**INEURO**	Alicia, Tornero Navarro
Sanlúcar de Barrameda	**Juan Luis, Abeledo Alcón**	Juan Luis, Abeledo Alcón
Madrid	**LEZCANO FISIOTERAPIA**	Lucía, Díez Fuentes
Vitoria	**NEUFIS**	Verónica, Montoya Murillo
Ferrol	**NEURAXIS**	Laura, Ares Barge;Natalia Muiño
Esplugues de Llobregat	**NEUROESPLUGUES**	Beatriz, Martín Lamata
Zaragoza	**CENTRO FISIOTERAPIA EL CARMEN**	Cristina, de Diego Alonso

Tabla 6*. Relación entre los profesionales colaboradores y los centros participantes en el proyecto de investigación Part&Sed-Stroke.*

4.3.Variables y herramientas de valoración

En este apartado se detallan las variables y herramientas de valoración utilizadas cuyos ítems volcados a la aplicación *Prevent for Work* [4] para el posterior análisis de los datos (*Figura 11*). Se profundizará especialmente en las variables y herramientas utilizadas en los estudios incluidos en la presente tesis, especialmente en IPAQ-SF y SDO-OB por ser las herramientas que han sido validadas en los ***artículos 2 y 3*** respectivamente. Al final del capítulo, se expone la relación de estas variables y herramientas con cada uno de los artículos que componen esta tesis doctoral (*Tabla 8, 9 y 10*).

A continuación, en la figura 11 se representa como fueron agrupadas en 4 bloques las variables y las herramientas de valoración pertenecientes al proyecto de investigación Part&Sed-Stroke, de las cuales no todas han sido utilizadas en los artículos de investigación de la presente tesis doctoral. El bloque 1 y 2 fue administrado por los profesionales colaboradores, y el bloque 3 y 4 administrado por el investigador principal y autor de esta tesis doctoral, quien también administró el bloque 1 y 2 a una submuestra de los participantes. Asimismo, en las figuras 12 y 13 se ilustra el proceso de recogida de los datos.

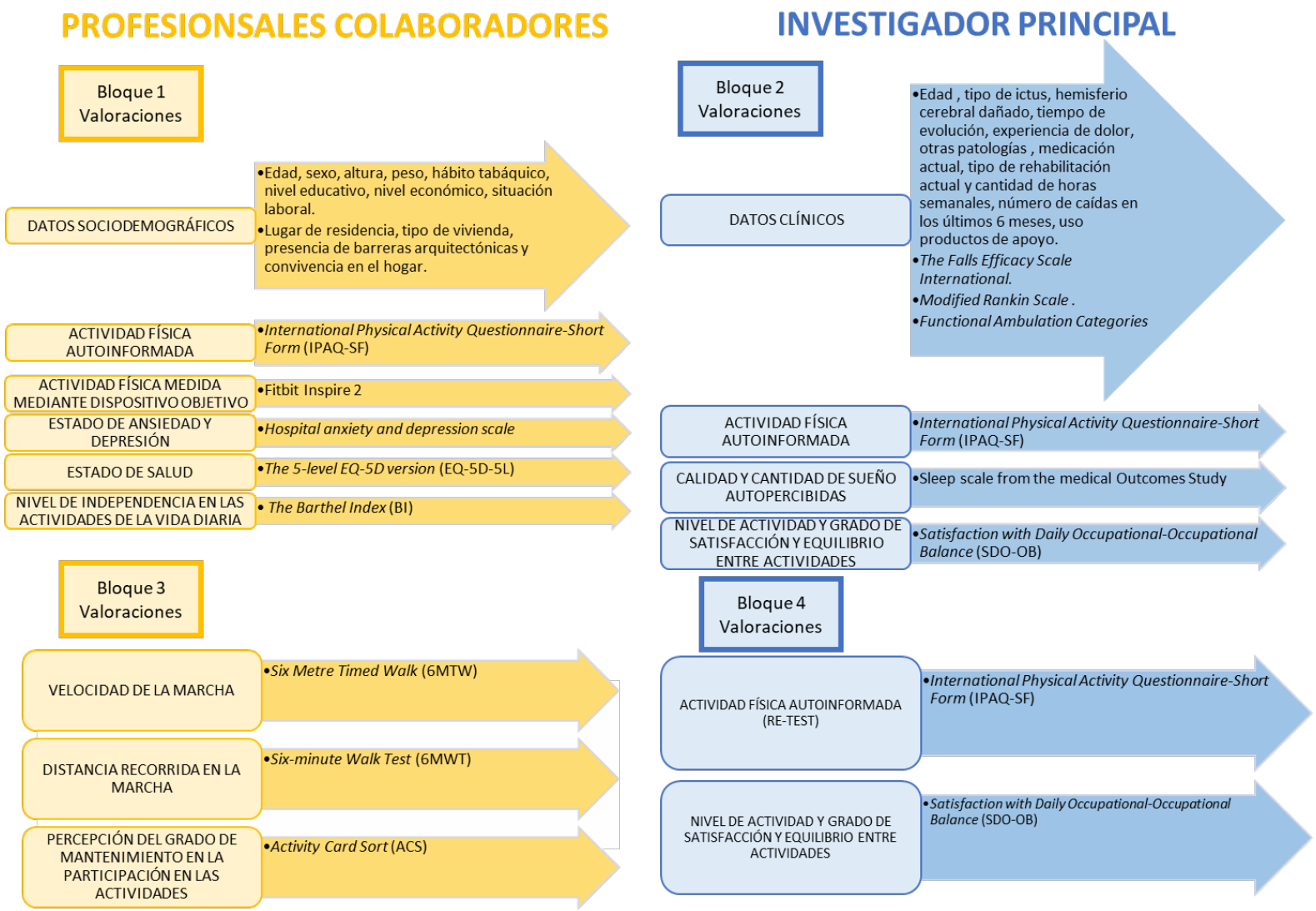


Figura 11. *Relación entre las variables, herramientas de valoración y persona responsable de su administración agrupados en cuatro bloques.*



Figura 12. *Procedimiento de parte de la recogida de la información a los participantes del estudio. A Colocación de la pulsera de monitorización Fitbit Inspire 2. B Vinculación de la pulsera de monitorización Fitbit Inspire 2 al dispositivo móvil. C Administración de cuestionarios autoreportados y registro de datos en aplicación Prevent for Work. D Administración de herramientas de valoración.*

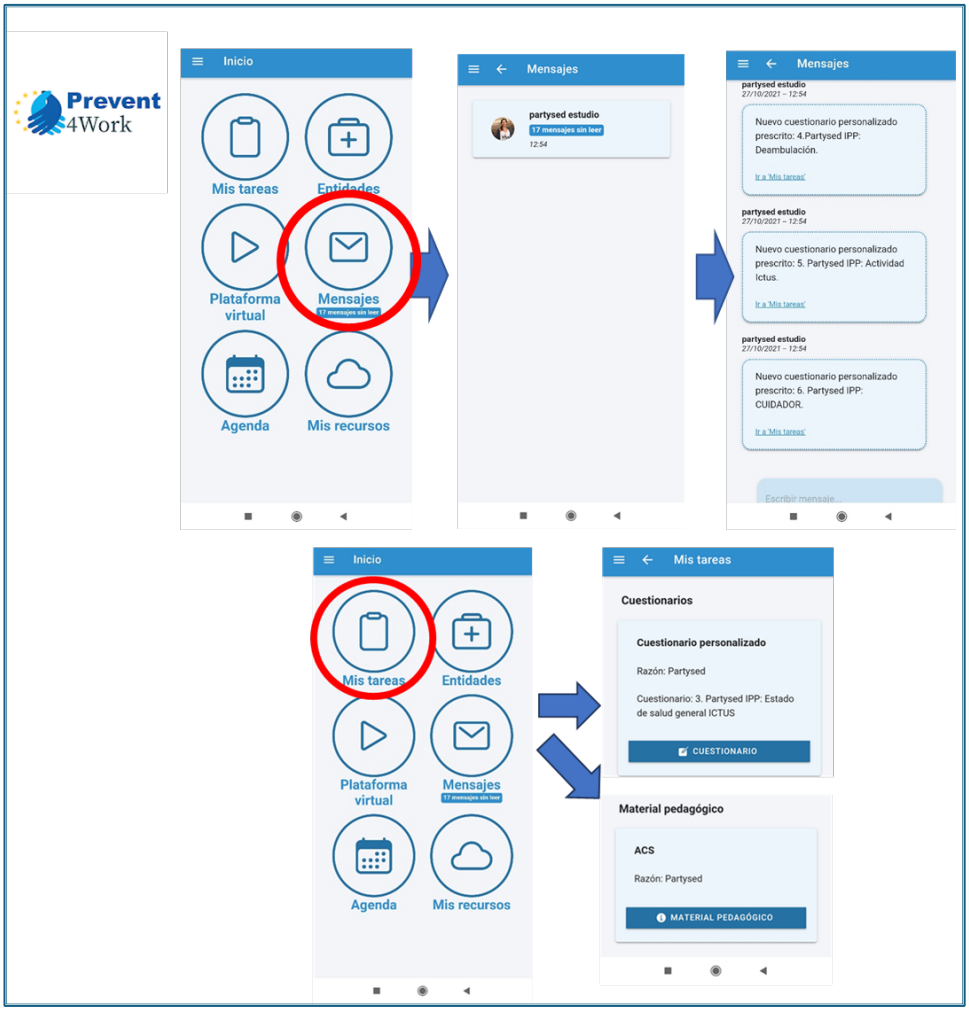


Figura 13. *Aplicación Prevent for Work. Ejemplo de mensajes recibidos por los profesionales colaboradores para registrar los datos de las herramientas de valoración a completar.*

4.3.1. Datos sociodemográficos

Los datos sociodemográficos incluyeron edad, sexo, altura y peso, situación laboral, municipio de residencia y convivencia en el hogar.

4.3.2. Datos clínicos

Los datos clínicos abarcaron información sobre la edad de los participantes, tipo de ictus, hemisferio cerebral dañado, tiempo de evolución y cantidad de horas semanales de rehabilitación, uso productos de apoyo y *The Functional Ambulation Categories* [5].

4.3.3. Cuestionario para evaluar el estado de salud

Se seleccionó el cuestionario de calidad de vida autoevaluada *The 5-level EQ-5D versión* (EQ-5D-5L) para evaluar el estado de salud actual. En esta herramienta, la persona debe indicar su calidad de vida en relación con la movilidad, el autocuidado, las actividades habituales, el dolor/malestar y la ansiedad/depresión a través de cinco posibles opciones de respuesta. En la segunda parte del cuestionario, la persona debe señalar su estado de salud actual en una escala de 0 a 100, donde 0 significa "el peor estado de salud imaginable" y 100 "el mejor estado de salud imaginable". EQ-5D-5L es una herramienta válida y fiable para evaluar la calidad de vida relacionada con la salud [6].

4.3.4. Cuestionario para evaluar el nivel de independencia en las actividades de la vida diaria

Para evaluar el nivel de independencia y movilidad en la realización de las actividades de la vida diaria también descritas como actividades básicas de la vida diaria se utilizó BI. La herramienta cuenta con 10 ítems para registrar la capacidad de los participantes para realizar las actividades básicas de la vida diaria entre las que se encuentran: alimentarse, bañarse, asearse, vestirse, controlar los esfínteres, controlar la vejiga, ir al baño, trasladarse en silla, caminar y subir escaleras. Cada ítem se puntúa indicando el nivel de dependencia o independencia, es decir la posibilidad de realizar la actividad sólo o con ayuda. Esta herramienta proporciona información valiosa sobre la discapacidad funcional en los supervivientes de un ictus [7]. Cuanto mayor es la puntuación, mayor es el

grado de independencia siendo la puntuación máxima de 100 puntos, lo que implica máxima independencia. Además, en función de la puntuación, se puede indicar que de 0 a 20 puntos implica una situación de dependencia total, de 21 a 60 dependencia severa, de 61 a 90 dependencia moderada y de 91 a 99 dependencia leve.

4.3.5. Cuestionario para evaluar la actividad física autoinformada

La AF autoinformada se evaluó con la versión para entrevista del IPAQ-SF en español que puede administrarse por videoconferencia [8]. El IPAQ-SF es un cuestionario autoinformado cuyo objetivo es determinar la frecuencia y el tiempo dedicado a la AFMV y a caminar en los últimos siete días, así como el tiempo que se pasa sentado durante un día de la semana como indicador del tiempo dedicado a la actividad sedentaria [9]. En este sentido, las actividades cubiertas por el IPAQ-SF incluyen la AF en el tiempo libre, las actividades domésticas y de jardinería, la AF relacionada con el trabajo y la AF relacionada con el transporte. La puntuación final se expresa en METs minutos a la semana (METs-min/semana) y clasifica los niveles de AF en bajos, moderados o altos (*Tabla 7*).

Específicamente, "niveles bajos de AF" se refiere a aquellos individuos que no cumplen los criterios de moderado o alto. "niveles moderados de AF" se refiere a cuando se informa de uno de los siguientes criterios: a) 3 o más días de AF vigorosa (AFV) de al menos 20 minutos al día; o b) 5 o más días de AF moderada (AFM) o caminar de al menos 30 minutos al día; o c) 5 o más días de cualquier combinación de caminar, AFMV alcanzando un mínimo de al menos 600 METs-min/semana. "niveles altos de AF" se refiere a cuando se informa de uno de los siguientes criterios 1) AFV al menos 3 días y acumulación de al menos 1500 METs-min/semana, o 2) 7 o más días de cualquier combinación de caminar, AFM, o AFV alcanzando un mínimo de al menos 3000 METs-min/semana [10].

- Niveles altos de AF alcanzados cuando se informa de uno de los siguientes criterios: • ≥3 días de AFV alcanzando ≥ 1500 METs-min/semana. • ≥5 días de cualquier combinación de marcha y AFMV alcanzando ≥3000 METs-min/semana.
- Niveles moderados de AF alcanzados cuando se informa de uno de los siguientes criterios: • ≥3 días de AFV alcanzando ≥20 minutos/día. • ≥5 días de AFM alcanzando ≥30 minutos/día. • ≥5 días de cualquier combinación de marcha y AFMV que logre ≥600 METs-min/semana.
- Niveles bajos de AF alcanzados cuando no se cumplen los criterios para niveles los moderados o altos de AF.

Tabla 7. *Categorías de niveles de actividad física según The International Physical Activity Questionnaire Short-Form. AF: actividad física; AFM: actividad física moderada; AFMV: actividad física moderada-vigorosa; AFV: actividad física vigorosa; MET: Metabolic Equivalents of Task.*

El IPAQ ha sido considerado una herramienta útil para el cribado de los supervivientes de un ictus crónicamente inactivos que requieren intervenciones específicas para promover hábitos saludables [11]. Tanto IPAQ-SF como *IPAQ- Long Form*, tienen propiedades psicométricas equivalentes [12], consideran las mismas dimensiones y expresan la puntuación final en las mismas unidades (es decir, minutos semanales en AFV, AFM, actividad de caminar, METs-min/semana total y tiempo sentado), facilitando la evaluación del cumplimiento de las recomendaciones de la OMS. En este sentido es posible utilizar la siguiente fórmula para dicho cálculo.

$$AFMV = AFM + (AFV \times 2)$$ [10]

Por lo tanto, el IPAQ, es una herramienta comúnmente utilizada para evaluar los niveles de AF en adultos [13] [14,15], que recientemente ha sido elegida a través de un consenso internacional para proporcionar datos sobre el tiempo de AFMV después de un ictus [16] a pesar de que se desconocen sus propiedades psicométricas cuando es administrada en estas personas.

4.3.6. Evaluación de la actividad física medida mediante dispositivo objetivo

Para evaluar el nivel de AF se utilizó la pulsera de monitorización de actividad Fitbit Inspire 2 (*Fitbit, Estados Unidos, San Francisco, CA*). Las pulseras Fitbit se consideran una herramienta válida y fiable para monitorizar la AF y las horas de sueño [17,18], procedimiento considerado válido en supervivientes de un ictus [19]. Pero hasta la fecha no se dispone de información sobre sus propiedades psicométricas. No obstante, han sido recomendadas por un reciente consenso internacional para supervivientes de un ictus [16]

El modelo Fitbit Inspire 2 dispone de un sistema de acelerómetros de 3 ejes que permite monitorizar los minutos de AF, el número de pasos, la frecuencia cardiaca y el gasto calórico. Para estos estudios, se colocaron las pulseras durante 14 días completos durante 24h horas en la muñeca menos afecta.

4.3.7. Evaluación de la Velocidad de la marcha

La velocidad de la marcha en metros por segundo se evaluó con la versión del test de 10 metros denominada *6-Metre Timed Walk* (6MTW). Para ello, se marcaron en el suelo los puntos de inicio y final de los 10 metros, así como los 2 primeros metros y los 2 últimos metros. Concretamente, se registró el tiempo que cada participante empleó en caminar 6 metros en un espacio comparable al suelo de un pasillo amplio con una superficie firme sin irregularidades ni distracciones, excluyendo los 2 metros iniciales y finales destinados a la aceleración y desaceleración. Se pidió a los participantes que caminaran a una velocidad cómoda y constante utilizando sus productos de apoyo habituales (p. ej., ortesis de tobillo o bastones) [20]. El valor final se determinó como la media de tres mediciones realizadas siguiendo las indicaciones para reducir el sesgo de medición.

4.3.8. Evaluación de la Distancia recorrida en la marcha

Se utilizó la prueba de *6-minute walk test* (6MWT) para evaluar la distancia recorrida caminando por el participante en 6 minutos. Durante la prueba se siguieron las directrices normalizadas en relación con las indicaciones verbales sobre el tiempo transcurrido y

refuerzos positivos sin ninguna otra indicación no permitida por la prueba. La prueba 6MWT se considera una herramienta fiable y válida para medir la distancia recorrida, la resistencia y la capacidad aeróbica en personas supervivientes de un ictus [21].

4.3.9. Cuestionario para evaluar el nivel de actividad, grado de satisfacción y equilibrio entre actividades

Se administró la versión española de SDO-OB [22-24]. Esta herramienta evalúa el nivel de actividad y el grado de satisfacción con la actividad y el equilibrio entre actividades aportando una visión subjetiva e individualizada de la persona con respecto a las restricciones en la participación en actividades. Es necesario tener en cuenta que la herramienta de valoración *The Satisfaction with Daily Occupations* se diseñó con el objetivo de evaluar el nivel de actividad y satisfacción de una persona según cuatro áreas de actividad (trabajo, ocio, gestión del hogar y autocuidado). Posteriormente, la herramienta *The Satisfaction with Daily Occupations* se amplió dando lugar a la herramietna SDO-OB, incluyendo preguntas sobre el equilibrio de la actividad en cada área de actividad [25]. En el SDO-OB, el equilibrio de actividades se refiere a la percepción del individuo de tener la cantidad y la variación adecuadas de actividades [26]. *The Satisfaction with Daily Occupations* se validó inicialmente en diversas poblaciones con problemas de salud mental en Suecia [27-29], pero también se utilizó con éxito en personas diagnosticadas con la Enfermedad de Parkinson [30]. Posteriormente, se ha validado una versión árabe de la herramienta *The Satisfaction with Daily Occupations* en una población con afecciones neurológicas [31], y una versión danesa en una población de solicitantes de asilo [32]. Finalmente se validó la versión española del SDO-OB en una población con problemas de salud mental [24].

El SDO-OB es una herramienta de valoración basada en una entrevista que aborda 13 ítems, organizados en cuatro áreas de la ocupación: trabajo, ocio, gestión del hogar y autocuidado. El SDO-OB evalúa mediante una entrevista estructurada el nivel de actividad, la satisfacción derivada de la realización de esta actividad y el equilibrio percibido entre las actividades, incluida la asignación de tiempo percibida (si hace muy poco, lo justo o demasiado) dentro de cada área. Para cada ítem, la persona encuestada debe indicar si ha participado recientemente o no (sí/no) y proporcionar una autocalificación del 1 al 7 en relación con el grado de satisfacción con esa situación (1=estar extremadamente insatisfecho y 7=estar extremadamente satisfecho). Las

respuestas afirmativas se suman en una puntuación de nivel de actividad y las puntuaciones de satisfacción se suman para formar la puntuación de satisfacción con la actividad. Además, las puntuaciones de equilibrio de la actividad se calificaron para cada área con el fin de evaluar si el encuestado realizaba suficientes, demasiadas o muy pocas de las actividades pertenecientes a esa área. Concretamente, se consideraron cinco respuestas: muy poco (-2), demasiado poco (-1), justo lo suficiente (0), demasiado (1) y mucho (2) [24]. Además, siguiendo recomendaciones anteriores [25], las puntuaciones se pueden agrupar para posteriores análisis en "infraocupado" (puntuación de -2 o -1), "en equilibrio" (puntuación de 0) y "sobreocupado" (puntuación de 1 o 2).

4.3.10. Cuestionario para evaluar la percepción del grado de mantenimiento en la participación en las actividades

Se utilizó la versión española ACS [37] para evaluar el grado de participación en actividades. Se trata de una herramienta recomendada para recoger información sobre los dominios de actividad y participación de la CIF en la población con ictus [33,34]. El ACS abarca todos los dominios de participación definidos por la CIF (es decir, aprendizaje y aplicación de conocimientos, tareas y demandas generales, comunicación, movilidad, autocuidado, vida doméstica, interacciones y relaciones interpersonales, áreas principales de la vida, vida comunitaria, cívica y social [35] excepto el dominio 2 tareas y demandas generales [36]. La versión española de ACS registra la participación en 79 actividades recopiladas a su vez en cuatro áreas de la participación que engloban 26 actividades instrumentales, 23 actividades de ocio, 27 actividades de participación social y 3 actividades productivas y educación.

A la persona se le muestran tarjetas con fotografías que reflejan estas actividades cotidianas. En una primera fase, la persona debe indicar si realizaba la actividad antes del inicio de la enfermedad. Posteriormente, se le volverán a mostrar las actividades que ha indicado que hacía antes y la persona debe indicar si las ha seguido haciendo como antes, si las hace con menos frecuencia o si ha dejado de realizarlas.

La puntuación final combina las cuatro áreas de participación e indica a través de un porcentaje el nivel de compromiso con cada actividad y si esa actividad se ha interrumpido. La ACS es una herramienta fiable y validada para medir el nivel percibido de participación en actividades [37].

Artículo	Diseño metodológico del estudio	Estudios	Criterios de elegibilidad	Variables y Herramientas de valoración
Artículo 1. ***The relationship between levels of physical activity and participation in everyday life in stroke survivors: a systematic review and meta-analysis.***	Revisión sistemática con metaanálisis bajo el marco de trabajo *The Population-Exposure-Outcome* [38] y según las directrices de la Guía PRISMA [39] registrado en the *International Prospective Register of Systematic Reviews database:* CRD42022360711.	49 artículos cumplieron los criterios de elegibilidad.	Tipo estudio: Estudios transversal o prospectivo con disponibilidad a texto completo en inglés o español. Características de los participantes: Muestra de >10 personas mayores de edad con diagnóstico de ictus. Características de las herramientas de valoración: dispositivo objetivo, autocuestionario u observación directa para obtener datos sobre actividad física y herramienta de valoración de la participación en al menos una actividad de la vida cotidiana.	Evaluación del riesgo de sesgo: - *Newcastle-Ottawa scale* (estudios de cohortes). - Versión adaptada de *Newcastle-Ottawa* (estudios transversales). - *PEDro scale* (estudios de ensayo clínico aleatorizados). Cambios significativos: En los resultados de actividad física o participación de los estudios prospectivos. Correlación: Entre los resultados de actividad física y participación.

Tabla 8. *Material y métodos del artículo 1 que compone la presente Tesis Doctoral.*

Estudio	Diseño metodológico	Participantes	Criterios de elegibilidad	Variables y herramientas de valoración
Articulo 2. ***Validity and stability of the International Physical Activity Questionnaire for stroke survivors with preserved walking ability.***	Estudio psicométrico: validez aparente, validez de contenido, fiabilidad test-retest. Siguiendo las recomendaciones de la *COnsensus-based Standards for the selection of health Measurement Instruments recommendations* [40].	n=114 (40 mujeres) supervivientes de un ictus. Edad: 61,4± 12,4 Tiempo desde el ictus: 3,5[1,7-6,9] años. *The Functional Ambulation Categories*: 3: 11% 4: 25% 5: 64% Ayuda para caminar: Ninguna 77(68%).	Personas mayores de edad, supervivientes de un ictus hace más de 6 meses, que residían en su propio domicilio (solos o en compañía de familiares u otras personas) y sin presentar alteración cognitiva o de comunicación que interfiriera en el registro de los datos, con capacidad de caminar de forma independiente, así como disponibilidad y capacidad de manejo de dispositivo móvil.	- Datos sociodemográficos (edad, sexo, altura, peso): cuestionario en aplicación *Prevent for Work..* - Datos clínicos (tiempo desde el ictus, tipo de ictus, hemisferio cerebral afectado, rehabilitación, uso de productos de apoyo, *The Functional Ambulation Categories*): cuestionario en aplicación *Prevent for Work..* - Actividad física autoinformada: IPAQ-SF. - Actividad física medida mediante dispositivo objetivo: Fitbit Inspire 2. - Velocidad de la marcha: 6MTW.
Artículo 3. ***Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors.***	Estudio psicométrico: validez de contenido, consistencia interna, validez convergente, validez de grupos conocidos, fiabilidad test-retest. Siguiendo las recomendaciones de la *COnsensus-based Standards for the selection of health Measurement Instruments* [40].	n=128 (47 mujeres) Supervivientes de un ictus. Edad: 61,8 ±12,4 años. Tiempo desde el ictus: 3,5 [1.7-7.0] años. Con necesidad de un cuidador: 68 (53%). BI: 85,4±17,6.	Personas mayores de edad, supervivientes de un ictus hace más de 6 meses, que residían en su propio domicilio y sin presentar alteración cognitiva o de comunicación que interfiriera en el registro de los datos, con disponibilidad y capacidad de manejo de un dispositivo móvil.	- Datos sociodemográficos (edad, el sexo, el nivel educativo, la situación familiar y la presencia o no de un cuidador principal): cuestionario en aplicación *Prevent for Work.* - Datos clínicos (fecha del ictus, el tipo de ictus, el hemisferio cerebral dañado y The Barthel Index): cuestionario en aplicación Prevent for Work. - Estado de salud: EQ-5D-5L. - Percepción del grado de participación en actividades: ACS. - Nivel de actividad y grado de satisfacción y equilibrio entre actividades: SDO-OB.

Articulo 4. ***Correlations between physical activity levels and participation in high-functioning stroke survivors.***	Estudio observacional transversal.	n= 130 (43 mujeres) Supervivientes de un ictus. Edad: 61,3 ±12,4 años. Tiempo desde el ictus: 62.4 meses FAC: 3: 8.9% 4: 22.0% 3: 8.9% BI: 89.6 ± 12.1	Personas mayores de edad, supervivientes de un ictus hace más de 6 meses, que residían en su propio domicilio (solos o en compañía de familiares u otras personas) y sin presentar alteración cognitiva o de comunicación que interfiriera en el registro de los datos, con capacidad de caminar de forma independiente, así como disponibilidad y capacidad de manejo de dispositivo móvil.	- Datos sociodemográficos (edad, sexo, situación laboral): cuestionario en aplicación *Prevent for Work*. - Datos clínicos (tiempo desde el ictus, tipo de ictus, FAC y BI): cuestionario en aplicación *Prevent for Work*. - Actividad física autoinformada: IPAQ-SF. - Actividad física medida mediante dispositivo objetivo: Fitbit Inspire 2. - Percepción del grado mantenimiento de participación después del ictus: ACS. - Nivel de actividad y grado de satisfacción y equilibrio entre actividades: SDO-OB.

Tabla 9. *Material y métodos de los artículos 2, 3 y 4 que componen la presente Tesis Doctoral.*6MTW: *6-Metre Timed Walk*; ACS: *The Activity Card Sort*; BI: *The Barthel Index*; EQ-5D-5L: *The 5-level EQ-5D*; IPAQ-SF: *The International Physical Activity Questionnaire - Short Form*; SDO-OB: *The Satisfaction with Daily Occupational-Occupational Balance*.

Estudio	Diseño metodológico	Participantes	Criterios de elegibilidad	Entrevista no estructurada	Entrevista semiestructurada
Artículo 5. ***"More than effort, it's dedicating time and perseverance." Experiences of physical activity and physical exercise in stroke survivor with high functional capacity: A qualitative study.***	Estudio cualitativo fenomenológico [2] siguiendo el marco de trabajo de Husserl's [3] .	n=35.	Personas mayores de edad supervivientes a un ictus hace más de 6 meses, que residían en su propio domicilio y no presentaban alteración cognitiva o de comunicación que interfiriera en el registro de los datos, con capacidad de caminar de forma independiente.	¿Cuál es su experiencia con la actividad física después de un ictus?	Antes del ictus, ¿cómo consideraba que era la actividad física y el ejercicio? ¿y ahora? ¿Qué aspectos influyen en que dedique más o menos días/horas a las actividades que puede realizar? Entre las actividades que realiza ahora, ¿cuáles le producen más satisfacción? ¿por qué? ¿por qué y cómo las realiza? ¿Qué información ha recibido sobre la actividad física que puede realizar para "combatir las secuelas del ictus"? ¿Qué actividades le resultan más agotadoras? ¿Qué actividad le resulta más fácil física y/o mentalmente?
Artículo 6. ***Taking part. Experiences surrounding the return to participation in stroke survivors. A qualitative study.***	Estudio cualitativo fenomenológico [2] siguiendo el marco de trabajo de Husserl's [3] .	n=35.		¿Puede decirme cómo le ha influido el ictus en su participación en las actividades de la vida diaria?	¿Qué tareas ya no realiza (tanto en casa como fuera de ella) ahora? ¿Qué actividades evita y por qué? ¿Qué tareas cotidianas que son importantes para usted dentro y fuera de casa ha recuperado actualmente después del ictus? ¿Qué factores le impulsan o le impiden reanudar las tareas después del ictus? ¿Para qué actividades necesita o pide ayuda y qué actividades puede hacer por sí mismo? ¿Qué hace ahora que no hacía antes (nuevas actividades)?

Tabla 10. *Material y métodos de los artículos 5 y 6 que componen la presente Tesis Doctoral.*

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CAPÍTULO 5: RELACIÓN DE ARTÍCULOS

En este apartado se expone el compendio de artículos que componen la presente Tesis Doctoral. Se presentan los artículos con su título, autores, afiliaciones, cuartil, factor de impacto y forma de citación acompañado del documento que ha sido publicado, está en fase de revisión o enviado.

Artículo 1. *de Diego-Alonso C, Bellosta-López P, Blasco-Abadía J, Buesa-Estéllez A, Roldán-Pérez P, Medina-Rincón A, López-Royo MP, Giner-Nicolás R, Doménech-García V, Fini NA. The relationship between levels of physical activity and participation in everyday life in stroke survivors: A systematic review and meta-analysis. Disabil Health J. 2024 May 16:101640. doi: 10.1016/j.dhjo.2024.101640. Epub ahead of print. PMID: 38777677.*

Artículo 2. *de Diego-Alonso C, Blasco-Abadía J, Doménech-García V, Bellosta-López P. Validity and stability of the international physical activity questionnaire short-form for stroke survivors with preserved walking ability. Top Stroke Rehabil. 2024 Oct 22:1-10. doi: 10.1080/10749357.2024.2417645. Epub ahead of print. PMID: 39436814.*

Artículo 3. *de Diego-Alonso C, Bellosta-López P, Hultqvist J, Vidaña-Moya L, Eklund M. Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors. Am J Occup Ther. 2024 May 1;78(3):7803205050. doi: 10.5014/ajot.2024.050454. PMID: 38640087.*

Artículo 4. *de Diego-Alonso C, Alegre Ayala J, Blasco-Abadía J, Doménech-García V, Bellosta-López P. Correlational study between physical activity levels and participation in high-functioning stroke survivors. Under Review.*

Artículo 5. *de Diego-Alonso C, Buesa-Estéllez A, Roldán-Pérez P, Bellosta-López P, Güeita-Rodríguez J. "More than effort, it's dedicating time and perseverance." experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study. Disabil Rehabil. 2024 Nov 25:1-9. doi: 10.1080/09638288.2024.2429753. Epub ahead of print. PMID: 39587442.*

Artículo 6. *de Diego-Alonso C, Buesa-Estellez A, Güeita-Rodriguez J, Bellosta-López J, Roldán-Pérez P. Taking part. Experiences surrounding the return to participation in stroke survivors. A qualitative study. Under Review.*

5.1. Revisión sistemática con metaanálisis: artículo 1

Artículo 1: The relationship between levels of physical activity and participation in everyday life in stroke survivors: a systematic review and meta-analysis

Cristina, de Diego-Alonso[1]; Pablo, Bellosta-López[1] ;Julia, Blasco-Abadía[1] ;Almudena, Buesa-Estéllez[1] ;Patricia, Roldán-Pérez[1];Almudena, Medina-Rincón[1]; María Pilar, López-Royo[1] ;Rafael, Giner-Nicolás[1] ;Víctor, Doménech-García[1] ;Natalie A, Fini2.

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Disability and Health Journal 2024 May 16:101640
(Editorial: ELSEVIER SCIENCE INC)
Q1, JIF:3.7
DOI: 10.1016/j.dhjo.2024.101640.

Citar como: *de Diego-Alonso C, Bellosta-López P, Blasco-Abadía J, Buesa-Estéllez A, Roldán-Pérez P, Medina-Rincón A, López-Royo MP, Giner-Nicolás R, Doménech-García V, Fini NA. The relationship between levels of physical activity and participation in everyday life in stroke survivors: A systematic review and meta-analysis. Disabil Health J. 2024 May 16:101640. doi: 10.1016/j.dhjo.2024.101640. Epub ahead of print. PMID: 38777677.*

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Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

The relationship between levels of physical activity and participation in everyday life in stroke survivors: A systematic review and meta-analysis

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ARTICLE INFO

Keywords:
Stroke
Physical activity
Participation
Daily life activities
Correlation

ABSTRACT

Background: Stroke survivors demonstrate decreased physical activity (PA) and take time to return to participation in everyday life, but the relationship between the two variables is unknown.
Objective: To investigate the correlation and trajectory over time between levels of PA and participation in everyday life in stroke survivors.
Methods: PubMed, Web of Science, Scopus, SPORTDiscus, Rehabilitation&Sport Medicine Source, and PEDro databases were searched from inception to January 2024.
Cross-sectional and prospective studies evaluating both levels of PA and participation in stroke survivors were included.
Two reviewers independently conducted the study selection, data extraction, and quality assessment. Meta-analyses of pooled correlation coefficients were calculated when at least two studies reported a correlation coefficient between the same PA and participation outcomes.
Results: Of 4962 studies identified, 49 were included in the systematic review. Studies were rated high (55%%) or fair (45%) quality. A wide range of monitoring methodologies for assessing PA and participation were found in the 23 prospective studies. Seven studies were included in the meta-analyses, showing a positive moderate correlation between PA time and participation in activities of daily living ($n = 148$; $r = 0.52$; $P < 0.01$; $I^2 = 81\%$) in participants <6 months post-stroke, and between PA time and the participation in all areas ($n = 126$; $r = 0.44$; $P < 0.01$; $I^2 = 0\%$) in participants ≥6 months post-stroke. Overall, while PA showed significant improvements over time, participation only showed a tendency.
Conclusions: Despite the heterogeneity, consistent positive associations were found between PA time and participation levels in some areas. Establishing consensus is crucial to reduce heterogeneity and facilitate data pooling.

1. Introduction

Stroke has a profound impact on an individual's life, increasing dependency and leading to significant health and socio-economic costs.[1,2] Stroke survivors often experience sequelae that result in impairments in bodily structures and functions, limiting their ability to perform daily activities and return to participation in everyday life.[1] Of particular importance is the extended time required for stroke survivors to return to full participation in everyday life,[3] participation is defined simply by the International Classification of Functioning, Disability and Health (ICF) as a person's involvement in life situations.[4] However, participation is a complex construct that implies not only performance but also subjective experience of meaning, autonomy, and self-determination.[4] It consists of a person's active involvement in carrying out daily life activities and finding them purposeful and meaningful.[5] It is a person-task-environment interaction that changes throughout life and responds to the demands of the environment and tasks.[6] The American Occupational Therapy Association grouped participation into activities of daily living, instrumental activities of daily living, sleep and rest, work, education, play, leisure and social participation.[7] Participation

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https://doi.org/10.1016/j.dhjo.2024.101640
Received 8 March 2024; Received in revised form 1 May 2024; Accepted 10 May 2024
Available online 16 May 2024
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restrictions are influenced by multiple factors,[8–10] encompassing personal factors, stroke-related sequelae,[3,11] the physical and social environment, as well as available resources.[12]

Many stroke survivors lead sedentary lifestyles[13] (defined as energy expenditure of 1.5 METs or less during awake time), spending prolonged periods of inactivity sitting or lying[14] and failure to adhere to the recommendations of the World Health Organization[15] on physical activity (PA). Physical activity is defined as "any bodily movement produced by skeletal muscles that results in energy expenditure".[16] Stroke survivors are inactive during all phases of recovery.[13] Numerous factors[17–21] may contribute to such behavior[22,23] or encourage a more active lifestyle,[24,25] including the influence of early life experiences and the effects of rehabilitation.[26]

Inadequate PA increases the risk of future cardiovascular events in stroke survivors.[27,28] Conversely, engaging in recommended levels of PA has a positive impact on neuroplasticity[29] and improves physical fitness, reducing the effects of stroke sequelae[30,31] as well as risk factors of a recurrent stroke.[32] It is well-documented that adopting a healthy lifestyle, including participation in daily life activities, can significantly contribute to overall well-being and health.[33,34] Consequently, there is a pressing need for up-to-date information on the impact of these factors on secondary prevention,[35,36] the most effective methods for measuring PA levels,[14,37–39] and strategies for facilitating a return to full participation.[40,41]

Low PA levels are a problem not only for stroke survivors with a high level of disability; but also for stroke survivors who return to independent walking.[10,42–44] Recent research[24] suggests a relationship between participation in daily life activities and PA levels, echoing earlier studies that explored the relationship between participation in everyday life and PA intensity.[44] Consequently, further investigation is needed to provide an updated synthesis of the scientific evidence on the relationship between these variables among stroke survivors.[45] Importantly, it remains unknown whether changes in PA levels and participation after a stroke are interrelated and whether this relationship varies depending on the time elapsed since stroke onset.

This study primarily aimed to investigate the relationship between PA and participation levels in stroke survivors. Furthermore, a secondary aim was to quantify whether levels of PA and participation in everyday life follow a similar trajectory over time.

2. Methods

2.1. Study design and registration

This systematic review and meta-analysis, conducted under the Population-Exposure-Outcome framework,[46] was reported following the PRISMA statement[47] and registered in the International Prospective Register of Systematic Reviews database (PROSPERO: CRD42022360711). The full protocol, including any minor deviations from the initial PROSPERO protocol, is available elsewhere.[45]

2.2. Eligibility criteria

2.2.1. Study types

Studies with a cross-sectional or prospective design (i.e., cohort and randomized controlled trials (RCTs)) that evaluated PA levels and participation levels in stroke survivors were included. Only articles with full-text availability and publication in an English or Spanish peer-reviewed journal were included. The search was not limited by the date of publication, but case studies or case series with a sample size of fewer than 10 participants were excluded.[48]

2.2.2. Participants characteristics

Studies recruiting adult participants (≥18 years) with a diagnosis of stroke, irrespective of the time since stroke or severity of stroke sequelae, etiology, sex, or geographical location, were included. Studies that involved mixed populations with composite data were excluded unless stroke-specific data could be extracted separately. The results were categorized based on the time elapsed since the stroke. Consequently, two groups were formed: (1) participants who experienced a stroke within the last 6 months, and (2) those whose stroke occurred more than 6 months before the beginning of the study.

2.2.3. Characteristics of the outcome measures

Studies reporting PA data according to recent international consensus were classified in the following sub-variables (1) PA frequency, (2) intensity and duration, (3) intensity, and (4) duration.[38] Theses sub-variables included measures such as metabolic equivalent of task (METs), minutes of total, vigorous or moderate PA, walking time, daily step count, total time spent in sedentary behavior, measured using objective devices (e.g., pedometers, accelerometers, fitness trackers, smartwatches) or self-reported questionnaires (e.g., International Physical Activity Questionnaire, Physical Activity Scale for the Elderly). Additionally the studies had to report information about participation in at least one daily life activity according to the occupational therapy framework,[49] including activities of daily living and instrumental activities of daily living, sleep and rest, work, education, play, leisure, or social participation using self-reported questionnaires (e.g., Stroke Impact Scale, Barthel Index, Frenchay Activities Index, or Activity Card Sort) or direct observation assessment (e.g., behavioral mapping), were included. Studies that solely included physical performance tests or energy expenditure in short laboratory sessions or PA performed during leisure time only were excluded. Furthermore, studies reporting correlation findings between PA and participation outcomes were considered for the meta-analysis.

2.3. Data sources and searches

Six electronic databases (Medline via PubMed; Web of Science and Scopus via Web of Science, managed by the Spanish Foundation for Science and Technology; SPORTDiscus and Rehabilitation & Sport Medicine Source via EBSCOhost; and PEDro) were searched from inception to January 2024. The search terms were categorized into three groups: stroke-related terms, terms related to PA, and terms related to participation in daily life activities. The search strategy of each database is provided in *Appendix A*. Aiming to identify additional records, a comprehensive review of the references included in the reviewed full-text articles was conducted.

2.4. Study selection

All studies found in the databases were downloaded and organized using Endnote Software (*Clarivate Analytics Philadelphia, USA*). Once duplicate records were eliminated, title and abstract screening was completed following predefined eligibility criteria. The full texts of the included studies were then carefully reviewed and assessed, applying the same eligibility criteria. At each step, two independent researchers (CDA and ABE) selected the studies, and in the event of any disagreements, a consensus was reached with the assistance of a third researcher (PBL).

2.5. Evaluation of the risk of bias in the studies

Two researchers (CDA and PRP) independently assessed the risk of bias of the studies using the Newcastle-Ottawa scale for cohort studies[50] and its adapted version for cross-sectional studies,[51] while the PEDro scale was used for RCTs.[52] A third researcher (PBL), who verified the assessments, resolved any discrepancies.

The Newcastle-Ottawa scale evaluates seven to eight items, grouped into three criteria: selection, comparability, and exposure or outcome. The maximum score is 9 (or 10 for cross-sectional studies). Articles with a score of at least 7 were classified as "high quality," those with a score of

4–6 were considered "fair quality," and those with a score less than 4 were categorized as "poor quality".[50]

The PEDro scale consists of 11 items, where articles are awarded 1 point if they meet the criterion and 0 points if not. Item 1 assesses external validity, items 2–9 assess internal validity, and items 10 and 11 assess the interpretability of the results. The maximum achievable score is 10 points since item 1 is not counted in the final score. Articles that score at least 6 out of 10 are considered "high quality," those scoring 4 or 5 are deemed "fair quality," and those with a score of less than 4 are labeled as "poor quality.[53]

2.6. Data collection

Two researchers (CDA and RGN) independently extracted data from the selected studies using a standardized data extraction sheet (*Appendix B*). Concurrently, a third and fourth researcher (PBL & AMR) cross-verified the extracted data and resolved any discrepancies.

The following data were collected: general study information, sample and subgroup characteristics, study characteristics, outcome measures, and outcome data related to PA and participation. Finally, the main results, including correlation coefficients between PA and participation outcomes, were extracted when available. The results were categorized based on the time elapsed since the stroke (i.e., <6 months or ≥6 months).

Whenever possible, patterns of PA and participation outcomes over time were extracted from prospective studies to identify significant changes. Significant improvements or deterioration in PA and participation outcomes were considered when there were statistically significant differences between the baseline and follow-up assessments. Conversely, if no significant changes were observed over time, it was categorized as "no change". As this review and meta-analysis do not intend to assess intervention effectiveness, it is essential to clarify that for RCTs, the treatment arms were considered as independent cohorts. This approach was intended to allow for a comprehensive understanding of how PA and participation may change over time and provide a comprehensive analysis of the data.[54]

2.7. Meta-analysis

When at least two studies reported a correlation coefficient between the same PA and participation outcomes, the weighted summary of correlation coefficients under the random effects model was calculated using the Hunter-Schmidt method, based on a weighted mean of the raw correlation coefficients.[55] Heterogeneity between the results of the included studies was investigated using I^2 statistics, with values > 50% indicating substantial heterogeneity across studies.[56] Correlations were considered as '*strong*' ($\rho \geq 0.70$), '*moderate*' ($0.40 > \rho < 0.69$), '*weak*' ($0.10 > \rho < 0.39$), or '*negligible*' ($\rho < 0.10$).[57] Subgroup analyses were conducted based on whether PA variables were measured by objective devices or self-reported questionnaires. Selection bias was examined by using funnel plots and Egger's tests. All analyses were conducted using STATA v.16.1 (*StataCorp, College Station, Texas 77845, USA*), and alpha was set at $P < 0.05$. Results from meta-analysis were also displayed in form of forest plots.

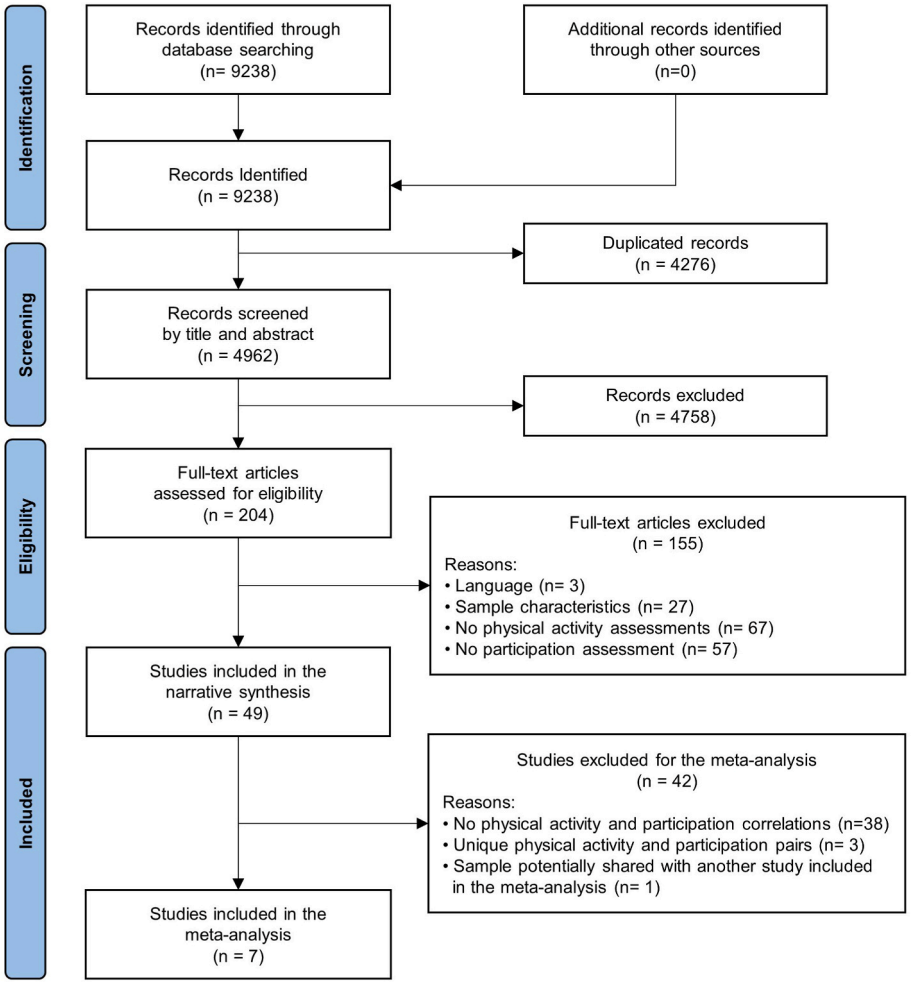


Fig. 1. Study flow-chart according to the PRISMA statement.

3. Results

3.1. Study selection

The article selection process of the articles is summarized in Fig. 1. After removing duplicates, 4962 records were identified. Two hundred and four full-text articles were screened as potential eligible studies, resulting in the inclusion of 49 studies in the review. The list of records excluded after full-text screening is presented in *Appendix C*. No additional records were identified within the bibliographic references of the reviewed full-text articles.

3.2. Study characteristics

The main characteristics of the articles included in this systematic review are presented in Table 1 for those including stroke survivors within 6 months post-stroke and in Table 2 after 6 months. The 49 articles comprising a total of 4554 stroke survivors (39% female). Twenty-four studies included stroke survivors within the first 6 months after stroke,[13,58–80] and 24 studies included stroke survivors recruited at least 6 months after stroke.[34,81–103] Only one study included both subgroups of stroke survivors as independent groups.[104]

3.3. Risk of bias assessment

The total Newcastle-Ottawa and PEDro scores for each study are integrated into Tables 1 and 2. Detailed tables showing the methodological quality assessment results of the retrieved studies are presented in *Appendix D*.

From the 26 cross-sectional studies, 14 studies (54%) were considered to be of high quality[67,68,70,76,80,84–86,91,93,94,97,102,103] and 12 studies (46%) of fair quality.[34,71,74,75,82,83,87,89,90,95,98,104]

From the 19 cohort studies, nine studies (47%) were considered to be of high quality[13,62–66,79,81,99] and 10 studies (53%) of fair quality.[58–60,69,72,73,77,78,92,96]

All four RCT's (100%) were considered to be of high quality.[61,88,100,101]

3.4. Physical activity

Of the articles included in the systematic review, 14 studies (29%) included self-reported questionnaires (e.g., International Physical Activity Questionnaire, Physical Activity Scale for the Elderly),[62,64,69,74,76,78,80,82,89,90,94,95,98,104] 27 studies (55%) included objective devices (e.g., ActiGraph, ActivPal),[13,34,58–60,65–68,70,72,73,75,81,83–86,88,91,92,96,97,99,100,102,103] of which only an article[102] includes Fitbit activity trackers, and eight studies (16%) included both subjective and objective measurement tools.[61,63,71,77,79,87,93,101]

Variables collected by self-reported questionnaires variables included: (1) intensity and duration (time spent in moderate to vigorous PA, light intensity PA), and/or (2) duration (total time spent in sedentary behavior, walking time, habitual weekly minutes of PA). Outcomes collected via objective devices included: (1) PA frequency (daily step count, number of activity counts), (2) intensity and duration (time spent in moderate to vigorous or light intensity PA), (3) intensity (energy expenditure by METs per day), and/or (4) duration (habitual weekly minutes of PA, total time spent in sedentary behavior and walking time).

3.5. Participation

Twelve studies (25%) recorded only activities of daily living (e.g., Barthel Index, Modified Barthel Index),[58,67,70,71,74–76,88–91,94] 21 studies (43%) used only a tool to assess the impact of stroke on all participation areas (e.g., Stroke Impact Scale-16, Stroke Impact Scale 3.0)[60,62,64,65,68,73,79,80,82-87,92,95-102], while only one study (2%) assessed both.[60] Seven studies (14%) used different assessment tools for other participation aspects (e.g., The Assessment of Life Habits, Activity Card Sort)[13,61,63,66,69,77,93] six studies (12%) used more than one participation assessment tool (e.g., Barthel Index and The Frenchay Activities Index).[34,60,72,81,104]

Only two studies (4%)[69,72] included direct observation assessment by using a behavior mapping protocol.

3.6. Meta-analysis

From the initial 49 studies, only 11 studies (22%) reported correlations between PA and participation outcomes within the first 6 months post-stroke[59,70,71,77,105] or greater than 6 months post-stroke.[85,87,95,97,99,103] Three of these studies were excluded from the meta-analysis due to investigating unique pairs of PA and participation outcomes (daily steps & Activity Card Sort, vs International Physical Activity Questionnaire & Activity Card Sort,[77] vs increase in daily steps & Stroke Impact Scale,[99] vs daily steps & Instrumental Activities of Daily Living[103]). Additionally, one study[70] was excluded due to likely inclusion of the same sample as another study.[71] We attempted to contact the authors but did not receive a reply.

Fig. 2 (<6 months since stroke) and Fig. 3 (≥6 months since stroke) show the forest plots for the pooled correlation coefficients between PA outcomes and participation from the included studies. No selection bias was detected after examining funnel plots and Egger's tests (Fig. 4).

Three studies, accounting for 148 individuals within 6 months post-stroke, investigated correlations between PA measures recorded by objective devices and participation in activities of daily living assessed through the Barthel Index, with the pooled coefficient showing a moderate correlation ($r = 0.52$; $P < 0.01$; $I^2 = 81\%$) (Fig. 2).

Four studies, accounting for 126 individuals greater than 6 months post-stroke, investigated correlations between PA time and participation in all areas by the Stroke Impact Scale, with the pooled coefficient showing a moderate correlation ($r = 0.44$; $P < 0.01$; $I^2 = 0\%$) (Fig. 3). Subgroup analyses also showed a moderate correlation between PA and participation when PA measures were recorded by self-reported questionnaires ($n = 50$; $r = 0.41$; $P < 0.01$; $I^2 = 28\%$) or objective devices ($n = 76$; $r = 0.45$; $P < 0.01$; $I^2 = 0\%$) (*Appendix E*).

The studies excluded from the meta-analysis due to analyzing unique pairs of outcomes[77,99,103] indicated a positive correlation between PA levels and participation levels. Specifically, for participants within 6 months since stroke, Thilarajah et al.[77] found a correlation between participation, recorded through the Activity Card Sort, and PA registered by using the International Physical Activity Questionnaire ($n = 55$; $r = 0.43$, $P < 0.05$) and a pedometer ($n = 55$; $r = 0.40$, $P < 0.05$). Meanwhile, Sullivan et al.[99] found that in people who had a stroke more than 6 months ago, the greater increase in the number of steps recorded with a pedometer, the greater the level of participation recorded by Stroke Impact Scale ($n = 11$; $r = 0.74$, $P < 0.05$). However, Levin et al.[103] only found a positive correlation between daily steps and the Instrumental Activities of Daily Living in a subsample of stroke survivors using a support device for walking ($n = 22$; $r = 0.51$, $P < 0.05$) but not in those who were able to walk independently ($n = 15$; $r = -0.18$, $P > 0.05$).

Furthermore, in participants within 6 months since stroke Barrett et al.[59] also found that lower participation in activities of daily living (Barthel Index) was associated with higher levels of sedentary behavior both during weekdays ($n = 19$; $r = -0.54$, $P = 0.02$) and weekends ($n = 19$; $r = -0.55$, $P < 0.05$).

3.7. Relationship between levels of physical activity and participation over time

The 23 prospective studies included in the systematic review[13,58–66,69,72,73,77–79,81,88,92,96,99–101] displayed high variability in the time points for measuring PA and participation.

Of the 16 prospective studies involving participants ($n = 1508$)

Table 1
Main characteristics of the included articles with **stroke survivors within 6 months post-stroke.**

Study	Design & Country	Participants (N, age, sex)	Stroke severity	PA measures	Participation measures	Results: changes over time and correlations	Quality assessment
Askim, 2013[54]	Cohort; Assessments at baseline,1, 3, & 6 months; Norway	N = 28; 78.7 ± 8.7 years; 46.4% female	SSS 41.2 ± 14.8	▪PAL 2® (right leg): time spent upright, sitting, and lying; number of transitions. -Duration of monitoring: between 1 and 3 complete days.	▪BI	PAL 2 ↑ BI N/A Correlations: N/A	6 Fair quality
Barrett, 2018[55]	Cohort; Assessments at baseline & 7 days before discharge; Canada	N = 19; 68.2 ± 9.8 years; 36.8% female	NIHSS 4.7 ± 3.3	▪Actiheart monitor® (chest): SB and PA time. -Duration of monitoring: 7 complete days	▪Activity log ▪BI	Actiheart monitor ≈ Activity Log ≈ BI N/A Correlations: PA time & BI: r = 0.37 Sedentary & BI: r = −0.54	6 Fair quality
Blaszcz, 2022[56]	Cohort; Assessment at baseline & 6 weeks; Poland	N = 31; 72.3 ± 6.5 years; 58.1% female	–	▪Caltrac® (affected hip): (over hip on the paresis side) -Duration of monitoring: 8.30 to 17.30 for 6 weeks	▪BI ▪SIS	Caltrac ↑ BI ≈ SIS ≈ Correlations: N/A	4 Fair quality
Brauer, 2022[57]	RCT; Assessment at baseline, 8 & 26 weeks; Australia	N = 119; - EG 62 ± 11 years; 20% female - CG 64 ± 9 years; 22% female	mRS - EG 2.8 ± 0.6 - CG 2.9 ± 0.6	▪activPAL3™ (anterior non-paretic thigh): Steps/day. ▪PASIPD -Duration of monitoring: 4 days	▪IPAQ	PASIPD ≈ activPAL3 ≈ IPAQ ≈ Correlations: N/A	8 High quality
Brounds, 2021[58]	Cohort; Assessment at baseline, 3 & 6 months; The Netherlands	N = 318; 60.4 ± 11.5 years; 36.4% female	–	▪IPAQ-SF	▪SIS ▪USER-P	IPAQ-SF ≈ SIS ↑ USER-P ↑ Correlations: N/A	7 High quality
Caetano, 2021[59]	Cohort; Assessment at baseline, 3 & 6 months; Brazil	N = 20; 64 ± 11 years; 20% female	–	▪Actigragh Wgt3X-BT® (waist non-paretic side): average step counts. Duration of monitoring: 7 days ▪IPAQ	▪LIFE-H	IPAQ ≈ Actigragh ≈ LIFE-H ≈ Correlations: N/A	8 High quality
Cook, 2020[60]	Cohort; Assessment at baseline & ≤3months; Sweden	N = 117; 68.4 ± 10.1 years; 41% female	mRS: 3(2–4)	▪SGPALS	▪SIS 3.9	SGPALS N/ASIS (ITEM 8) N/A Correlations: N/A	8 High quality
de Graaf, 2022[61]	Cohort; Assessment at baseline, 6 &12 months; The Netherlands	N = 200; 67.8 ± 11.2 years; 68% female	NIHSS 4.4 ± 4.4 -Sedentary exercisers:3.8 ± 3.9 -Sedentary movers:3.6 ± 3.5 -Sedentary prolongers:4.7 ± 4.7	▪Activ8® (thigh): SB, LPA, and MVPA time. -Duration of monitoring: 2 weeks during waking hours	▪SIS–P	Activ8 N/A SIS–P ↑ Correlations: N/A	9 High quality
de Rooji, 2021[62]	Cohort; Assessment at baseline & 6 weeks; The Netherlands	N = 52; 61.6 ± 10.5 years; 30.8% female	–	▪DynaPort MM® (middle of the lower back): walking activity. -Duration of monitoring: 5 days	▪USER-P	DynaPort ≈ USER-P ↑ Correlations: N/A	7 High quality
Egerton, 2006[63]	Cross-sectional; Assessment at baseline; UK	N = 41; 68.2 ± 11.3 years; 46.3% female	–	Pressure transducer (unaffected leg): upright activity time, number of transitions from nonupright to upright. -Duration of monitoring: one therapeutic day from 7 to 8am until 4.30pm	▪BI	Correlations: Upright activity time & BI: r = 0.79	7 High quality
Ezeugwu, 2017[64]	Cross-sectional; Assessment at baseline; Canada	N = 30; 63.8 ± 12.39 years; 43.3% female	–	▪actiPAL3 Micro® (thigh of non-hemiparetic leg): sleep duration, SB time, PA time, transitions to upright. -Duration of monitoring: 7 days	▪SIS	Correlations: N/A	8 High quality
Honado, 2023[100]	Cross-sectional; Assessment at baseline; Benín	N = 60; 56.7 ± 10.4 years; 26.7% female	–	▪IPAQ-SF	▪BI ▪RNLI	Correlations: N/A	5 Fair quality

(*continued on next page*)

Table 1 (*continued*)

Study	Design & Country	Participants (N, age, sex)	Stroke severity	PA measures	Participation measures	Results: changes over time and correlations	Quality assessment
Janssen, 2014[65]	Cohort; Assessment at baseline & 2 week; Australia	N = 14; 78 [68–81] years; 36% female	NIHSS 3(2–8)	▪Behavioral mapping checklists (48h direct observation)	▪Behavioral mapping checklists	Behavioral mapping checklists N/A Correlations: N/A	4 Fair quality
Lacroix, 2016[66]	Cross-sectional; Assessment at baseline; France	N = 21; 63 ± 20 years; 43% female	–	▪SenseWear armband® (unaffected arm): PA time. -Duration of monitoring: 1 day (from 9am to 4.30pm)	▪BI	Correlations: PA time & BI: r = 0.34	5 High quality
Lacroix, 2016[67]	Cross-sectional; Assessment at baseline; France	N = 88; 66 ± 17 years; 41% female	–	▪SenseWear armband® (unaffected arm): PA time. -Duration of monitoring: 2 days from 9am to 4.30pm	▪BI	Correlations: PA time & BI: r = 0.34	7 Fair quality
Rosbergen, 2017[68]	Cohort; Assessment at baseline & 3 months; Australia	N = 90; 76.0 ± 12.8 years; 37.7% female -Usual care N = 30; 76.0 ± 12.8 years; -Enriched N = 30; 76.7 ± 12.1 years; -Sustainability N = 30; 73.8 ± 17.4 years	NIHSS Usual care 8.5 ± 6.4 Enriched 7.8 ± 5.8 Sustainability 7.0 ± 4.8	▪Behavioral mapping	▪MBI ▪Behaviour mapping protocol	Behavioral mapping↑ MBI N/A Correlations: N/A	6 Fair quality
Shaughnessy, 2005[69]	Cohort; Assessment at baseline & 3 months; USA	N = 19; 68 ± 12.8 years; 47.3% female	–	▪SAM® (n/a): daily steps count.	▪SIS	SAM ↑ SIS ≈ Correlations: N/A	4 Fair quality
Skarin, 2013[70]	Cross-sectional; Assessment at baseline; Sweden	N = 104; 70.3 ± 14.4 years; 47.1% female	NIHSS 8(4–18)	▪Behavioural mapping ▪ACs	▪BI	Correlations: N/A	6 Fair quality
Strommen, 2014[71]	Cross-sectional; Assessment at baseline; Denmark	N = 57; 70.2 ± 13.4 years; 49% female	NIHSS 3(1–7) mRS 2 (1–3)	▪Actical Accelerometer® x5 (both wrists, both ankles, right anterior superior iliac spine): activity counts -Duration of monitoring: 7 days	▪BI	Correlations: N/A	6 Fair quality
Stroud, 2009[72]	Cross-sectional; Assessment at baseline; USA	N = 673; – 43.4% female	–	▪Self-reported PA questions	▪BI	Correlations: N/A	7 High quality
Thilarajah, 2020[73]	Cohort; Assessment at baseline & 3 months; Singapore	N = 55; 59(49–67) years; 36% female	NIHSS: 6 (4–10)	▪BMA250 triaxial accelerometer® (ankle): steps/day ▪IPAQ-S7 -Duration of monitoring: 4 days daytime	▪ACS-HDL	BMA250 N/ AIPAQ-S7 N/A ACS-HDL N/A Correlations: BMA250 & ACS: r = 0.40 IPAQ-S7 & ACS: r = 0.43	6 Fair quality
Tieges, 2015[10]	Cohort; Assessment at baseline, 1, 6 & 12months; UK	N = 96; 72.2 [64–80] years; 33.3% female	mRS: 2(1–3)	▪activPAL activity monitor® (unaffected thigh): SB time (bouts of time spent in sitting-lying). -Duration of monitoring: 7 days	▪NEADL	activPAL ≈ NEADL≈ Correlations: N/A	7 High quality
Tse, 2017[74]	Cohort; Assessment at baseline, 3 & 12 months; Australia	N = 185; 67 ± 13 years; 34% female	mRS: 1(1–2)	▪RAPA	▪WSAS ▪SIS 3.0	RAPA N/A WSAS N/ASIS 3.0 N/A Correlations: N/A	6 Fair quality
Wondergem, 2022[75]	Cohort; Assessment at baseline, 6, 12 & 24 months; The Netherlands	N = 200; 67.8 ± 11.2 years; 36% female	NIHSS: No symptoms: 13.0; Minor symptoms: 55.5; Moderate to severe symptoms: 31.5	▪Activ8® (thigh): SB time, LPA, MVPA. ▪SIS-PHYSICAL -Duration of monitoring: 14 days	▪SIS	SIS-PHYSICAL N/ AActiv8 N/A SIS N/A Correlations: N/A	8 High quality
Zirnsak, 2022[76]	Cross-sectional; Assessment at baseline; Germany	N = 481; 69.6 ± 12.5 years; 41.2% female	mRS: 2 ± 3.0 NIHSS: 2.8 ± 3.9	▪IPAQ	▪SIS	Correlations: N/A	9 High quality

General abbreviations: G: Group; N: simple size; N/A: not available; r: correlation coefficient; LPA: light physical activity; mRS: modified Rankin Scale; MVPA: moderate to vigorous physical activities; NIHSS: National Institute of Health Stroke Scale; RCT: randomized controlled trial; SB: sedentary behaviour (sitting or lying position during waking hours); SSS: Scandinavian Stroke Scale. TCMSA-AI: The telephone interview version of the Chedoke-McMaster Stroke Assessment–Activity

Inventory.

Symbols: ≈: non-significant change over time; ↑: significant increase/improvement over time; ↓: significant decrease/deterioration over time.

Physical Activity assessments: ACs: activity categories; ACS-HDL: high-demand leisure activity section of the Activity Card Sort; IADL: Instrumental Activities of Daily Living; IPAQ: International Physical Activity Questionnaire; IPAQ-AF: the Africa francophone version of the International Physical Activity Questionnaire; IPAQ-LF: International Physical Activity Questionnaire Long Form; IPAQ-SF: International Physical Activity Questionnaire Short Form; IPAQ-S7: International Physical Activity Questionnaire-Short 7 Days; PASE: Physical Activity Scale for the Elderly; PASIPD: The physical activity scale for individuals with physical disabilities; PIEL: Participation in Everyday Life; RAPA: The Rapid Assessment of Physical Activity; SGPALS: Saltin Grimby 6-Level Physical Scale; SIS-PHYSICAL: Physical domain of the Stroke Impact Scale.

Participation assessments: EMA: Ecological Momentary Assessment; BI: Barthel Index; FAI: Frenchay Activities Index; IPAQ: Impact on Participation and Autonomy Questionnaire; LIFE-H: The Assessment of Life Habits Questionnaire; MBI: modified Barthel Index; NEADL: The Nottingham Extended Activities of Daily Living Questionnaire; RNLI: Reintegration to Normal Living Index; SIS: Stroke Impact Scale; SIS–P: Stroke Impact Scale participation subscale; USER-P: Utrecht Scale for Evaluation of Rehabilitation-Participation; SAM: Step-watch Activity Monitoring; WSAS: Work and Social Adjustment Scale.

within 6 months post-stroke,[13,58–66,69,72,73,77–79] 14 collected data within the first 3 months of the study,[13,58–64,66,69,72,73,77,78] showing significant increases in PA levels and a trend of change in the level of participation during this short period, where only one study confirmed a significant increase.[72] Only one study[62] showed a significant increase in participation levels. Among the eight studies recording data beyond 3 months of study commencement,[13,58,61–63,65,78,79] a tendency to increase PA levels was also observed, with only one study[65] demonstrating significant increases in participation levels.

From the seven studies conducted in participants (n = 732) greater than 6 months post-stroke,[81,88,92,96,99–101] four studies indicated an increasing trend, of which only two found significant increases both in PA levels and participation levels.[88,100] One showed no significant changes over time,[96] and the rest did not provide data or the results were not significant, even though they showed a tendency of improvement over time.

4. Discussion

This systematic review with meta-analysis is the first to comprehensively collate scientific evidence on PA and participation in stroke survivors. The review encompasses 49 studies comprising 1491 stroke survivors within the first 6 months after a stroke and 3063 stroke survivors recruited at least 6 months after a stroke. The meta-analysis of seven studies revealed positive correlations between PA and participation levels in stroke survivors both within and greater than 6 months post-stroke. The levels of PA appeared to increase in the first weeks or months compared to participation levels, which needed more time to show significative improvements. The results were influenced by various factors, including study design, research objectives, and the psychometric properties of the assessment tools. This review serves as a preliminary exploration, highlighting the necessity for further research with studies specifically designed to investigate the correlation between PA and participation both cross-sectionally and longitudinally.

The studies included in this review primarily utilized the Barthel Index within the first 6 months or the Stroke Impact Scale after 6 months to document significant changes in participation. While there is a discernible trend toward a change in the level of participation, it has been significantly demonstrated in only 2 studies. Further research is needed to thoroughly investigate these changes. Despite the limited number of studies included, this review validates the previously hypothesized assumption that returning to participation in everyday life after a stroke requires more than 6 months, challenging the prior belief that no significant change is possible after this period.[106] Previous studies specifically indicate that it may take up to 4 years to regain pre-stroke participation in daily life activities,[10] and 6 years to return to community participation.[8,107] This suggests that it may be necessary to monitor stroke survivors over a longer period to identify significant improvements in participation, as indicated by previous studies.[8,10,107]

It is noteworthy that among the 25 articles that included individuals who had a stroke more than 6 months ago, only 12 articles[81,82,86,90,93,95–97,99,102–104] included people who had a stroke more than 4 years ago, and only 8 articles[81,82,86,90,99,102–104] included individuals who had a stroke more than 6 years ago. It is evident that there is a need to investigate whether the changes that occur in the reorganization of the nervous system[108] after 6 months are transferred to the return to both participation[109] and active lifestyle, and how this process evolves over time and with aging.[3,110]

This systematic review reveals a high degree of heterogeneity in the tools used to record PA variables through objective devices or self-reported questionnaires and the participation variable through self-reported questionnaires. While most of the studies included in this research adhere to the recommendations of a recent consensus on PA variables and tools,[38] the same cannot be said for the measures of participation. The tools primarily used (do not provide comprehensive information (e.g., level of participation in different daily life activities,[7,111] restriction or dependence in participation or changes in participation due to disease[40,41]). The Barthel Index only covers the level of participation in the performance of activities of daily living, while the Stroke Impact Scale is the most widely used tool to measure participation in stroke survivors[41]; however, it does not uniformly cover the 9 activity and participation domains of the ICF[12] and do not include other aspects of the participation construct such as the meaningful subjective experience of participation or perceived autonomy[4,7] Therefore, the information provided in this review about the correlation between PA and participation (measured with Barthel Index and Stroke Impact Scale) may be incomplete. Further efforts are required to identify a comprehensive outcome measure for participation, given the current lack of consensus.[112]

4.1. Research implications

This systematic review with meta-analysis emphasizes the need to enhance scientific research not only within the initial months following a stroke but also beyond 6 months. In such studies, it is crucial to utilize recommended assessment tools for measuring PA and establish a standardized participation measure that cover the different aspects of the participation domain apart from performance. Additionally, establishing a consensus on the optimal timing of measurements to capture significant changes for each variable is imperative. Furthermore, future scientific publications should include all necessary data and information, including supplementary materials. This will facilitate the analysis of data in subsequent meta-analyses and contribute to the translation of findings into clinical care.

4.2. Clinical implications

This systematic review has demonstrated a progressive increase in participation associated with the increase in PA. This interrelationship underscores the importance of inter-disciplinary collaboration in rehabilitation clinical practice when striving for PA and participation goals, along with the careful selection of validated tools and optimal clinical assessment timepoints to capture changes.

Table 2
Main characteristics of the included articles with **stroke survivors greater than 6 months post-stroke.**

Study	Design & Country	Participants (N, age, sex)	Stroke severity	PA measures	Participation measures	Results: changes over time and correlations	Quality assessment
Aguiar, 2020[97]	RCT; Assessment at baseline, 12 & 16 weeks; Brazil	N = 22; -EG: 52 ± 11 years; 27.2% female -CG: 48 ± 10 years; 27.2% female	–	▪SenseWear Mini® (unaffected arm): PA time. ▪Human Activity Profile -Duration of monitoring: 7 days	▪SIS 3.0	SenseWear Mini ≈ Human Activity Profile ≈ SIS 3.0 N/A Correlations: N/A	8 High quality
Barclay, 2021[77]	Cohort; Assessment at baseline, 6 & 12 months; Canada	N = 13; 61.5 ± 15.5 years; 61.5% female	–	▪ActiGraph GT3X+® (unaffected ankle): steps/day. -Duration of monitoring: waking hours/1week	▪RNL ▪SIS ▪TCMSAAI	ActiGraph GT3X+ ≈ RNL ≈ SIS N/A TCMSA-AI N/A Correlations: N/A	7 High quality
Danielsson, 2011[78]	Cross-sectional; Assessment at baseline; Norway	N = 31; 59.7 ± 8.1 years; 29% female	mRS: 3 ± 1	▪PASE	▪SIS	Correlations: N/A	5 Fair quality
English, 2016[79]	Cross-sectional; Assessment at baseline; Australia	N = 50; 67.2 ± 11.6 years; 34% female	NIHSS n(%) No symptoms: 8 (16%) Mild: 25 (50%) Moderate: 16 (32%) Severe: 1 (2%)	▪activPAL3® (anterior thigh): sitting/lying, standing and stepping- Duration of monitoring: 14 days ▪Actigraph GT3X+® (non-paretic hip): MVPA -Duration of monitoring: 7 days	▪SIS	Correlations: N/A	6 Fair quality
Espernberger, 2022[30]	Cross-sectional; Assessment at baseline; Australia	N = 19; 74 ± 11 years; 52% female	–	▪ActivPAL3® (unaffected thigh): Steps/day, transitions, walking time and SB time. -Duration of monitoring: 7 days	▪BI ▪FAI	Correlations: N/A	4 Fair quality
French, 2016[80]	Cross-sectional; Assessment at baseline; USA	N = 59; 59 ± 11.2 years –	–	▪SAM®(ankle non-paretic lower extremity): steps/day -Duration of monitoring:3 days	▪SIS	Correlations: N/A	7 High quality
Fulk, 2010[81]	Cross-sectional; Assessment at baseline; USA	N = 19; 65.7 ± 11.9 years –	–	▪SAM® (ankle non-paretic lower extremity): steps/day -Duration of monitoring: 1 week	▪SIS	Correlations: PA time & SIS: r = 0.18	7 High quality
Fulk, 2017[82]	Cross-sectional; Assessment at baseline; USA	N = 441; 61.4 ± 12.4 years; 41% female	–	▪SAM® (ankle non-paretic lower extremity): steps/day -Duration of monitoring: between 2 and 7 days	▪SIS–P	Correlations: N/A	8 High quality
Giray, 2022[83]	Cross-sectional; Assessment at baseline; Turkey	N = 25; 55.0 ± 10.8 years; 32% female	–	▪Actical® (nonparetic hip): SB and PA time total activity counts, energy expenditure, and step/day. ▪PASE -Duration of monitoring: 3 weekdays	▪SIS 3.0	Correlations: PASE & SIS: r = 0.49 PA time & SIS: r = 0.50 Sedentary & SIS: r = 0.34	6 Fair quality
Grau-Pellicer, 2019[84]	RCT; Assessment at baseline & 3 months; Spain	-EG: N = 24; 63.0 ± 11.9 years; 45.8% female -CG: N = 17; 68.5 ± 11.5 years; 52.9% female	–	▪APP monitoring + Pedometer UW100, UW101 A&D® (positioning N/A): step/day, activity/sedentary behavior, walking distance and walking speed. -Duration of monitoring: 8 weeks	▪BI	APP & Pedometer ↑ BI ↑ Correlations: N/A	6 High quality
Hoang, 2012[85]	Cross-sectional; Assessment at baseline; France	N = 32; 64.6 ± 11.2 years; 34% female	–	▪Dijon Physical Activity Score	▪BI	Correlations: N/A	6 Fair quality
Honado, 2023[100]	Cross-sectional; Assessment at baseline; Benín	N = 60; 56.7 ± 10.4 years; 26.7% female	–	▪IPAQ-AF	▪BI ▪RNLI	Correlations: N/A	5 Fair quality
Jönsson, 2014[86]	Cross-sectional; Assessment at baseline; Sweden	N = 145; 74.4/78.1 (28–97); 41%female	mRS no symptoms: n = 39(27%) mRS no significant disability or slight: n = 64 (34%) mRS moderate or severe	▪Self-reported PA questions	▪BI	Correlations: N/A	5 Fair quality

(*continued on next page*)

Table 2 (*continued*)

Study	Design & Country	Participants (N, age, sex)	Stroke severity	PA measures	Participation measures	Results: changes over time and correlations	Quality assessment
			disability: n = 27 (19%)				
Joseph, 2017[87]	Cross-sectional; Assessment at baseline; South Africa	N = 45; 58.4 ± 13.7 years; 48.8% female	NIHSS: 4.4 ± 5.0	▪Actigraph GT3X® (unaffected hip): PA time, steps/day, activity count -Duration of monitoring: 5 days during waking hours	▪BI	Correlations: N/A	8 High quality
Kringle, 2020[88]	Cohort; Assessment at baseline, 6, 11 & 18 months; USA	N = 21; 70.8 ± 10.9 years; 61.9% female	–	▪ActivPAL micro3® (unaffected thigh): sitting time. -Duration of monitoring: 7 days	▪SIS–P	ActivPAL N/A SIS–P N/A Correlations: N/A	5 Fair quality
Koffman, 2023[98]	Cross-sectional; Assessment at baseline; USA	N = 70; 61 ± 13 years; 45.7% female	–	▪Fitbit Inspire 2 (unaffected wrist): step/day -Duration of monitoring: 2 weeks	▪SIS-16	Correlations: N/A	8 High quality
Lau, 2022[89]	Cross-sectional; Assessment at baseline; USA	N = 40; 52.8 ± 7.5 years; 42.5% female	–	▪ActivPAL® (anterior unaffected thigh): METs. -Duration of monitoring:7 days ▪IPAQ-LF	▪PIEL Survey App (8 EMA surveys every 2h/7 days, 8am10pm)	Correlations: N/A	8 High quality
Levin, 2023[99]	Cross-sectional; Assessment at baseline; Israel	N = 37; 59.0 [54.0–64.5] years; 37.8% female	–	▪Acticial Minimitter Co. (affected hip): Step/day -Duration of monitoring: 3 days	▪IADL questionnaire	Correlations: Steps/day & IADL: r = −0.18 (independent walkers: n = 12); r = 0.51 (device-users n = 22)	8 High quality
Nuñez Filha, 2020[90]	Cross-sectional; Assessment at baseline; Brazil	N = 53; 55.0 ± 13.4 years; 49%female	–	▪IPAQ	▪MBI	Correlations: N/A	8 High quality
Plow, 2017[91]	Cross-sectional; Assessment at baseline; USA	N = 25; 64.1 [46–89] years; 48% female	–	▪Godin Leisure Time Exercise Questionnaire	▪SIS16	Correlations: PA time & SIS: r = 0.41	4 Fair quality
Rowland, 2022[92]	Cohort; Assessment at baseline & 6 weeks; USA	N = 40; 58 ± 11 years; 35.4% female	–	▪SAM® (positioning N/A): Step/day -Duration of monitoring: N/A	▪SIS	StepWatch Activity Monitor (Average daily step count) = SIS–P = Correlations: N/A	5 Fair quality
Sánchez-Sánchez, 2021[93]	Cross-sectional; Assessment at baseline; Spain	N = 57; 58.2 ± 11.1 years; 35% female	mRS no significant disability or slight: n = 36 (63.2%) mRS moderate or severe disability: n = 21 (36.8%)	▪Actigraph wGT3XBT® (nonparetic hip): SB time, LPA time, MVPA time. -Duration of monitoring: ≥7 days over daytime	▪SIS-16	Correlations: PA time & SIS: r = 0.50	9 High quality
Sheng, 2021[94]	Cross-sectional; Assessment at baseline; China	N = 122; 65.5 ± 10 years; 40.16% female	–	▪SGPALS	▪SIS	Correlations: N/A	5 Fair quality
Sullivan, 2014[95]	Cohort; Assessment at baseline & during 6 weeks; USA	N = 11; 60.4 ± 12.1 years; 45.45% female	–	▪330 Step Pedometer® (unaffected hip): daily steps -Duration of monitoring: 7 days over 6 weeks	▪SIS-16	330 Step Pedometer ≈ SIS-16 ≈ Correlations: Steps increase & SIS: r = 0.74	8 High quality
Swank, 2020[96]	RCT; Assessment at baseline, 1 & 3 months; USA	N = 73; -G1:61.2 ± 16.9 years; 51.4% female -G2:61.3 ± 15.2 years; 41.7% female	NIHSS G1: 6.2 ± 3.5 NIHSS G2: 10.2 ± 6.6	▪Actigraph GTX3® (unaffected waist): SB and PA times. -Duration of monitoring: 3 consecutive days	▪SIS	Actigraph GTX3↑ SIS↑ Correlations: N/A	6 High quality

General abbreviations: G: Group; N: simple size; N/A: not available; r: correlation coefficient; LPA: light physical activity; mRS: modified Rankin Scale; MVPA: moderate to vigorous physical activities; NIHSS: National Institute of Health Stroke Scale; RCT: randomized controlled trial; SB: sedentary behaviour (sitting or lying position during waking hours); SSS: Scandinavian Stroke Scale. TCMSA-AI: The telephone interview version of the Chedoke-McMaster Stroke Assessment–Activity Inventory.

Symbols: ≈: non-significant change over time; ↑: significant increase/improvement over time; ↓: significant decrease/deterioration over time.

Physical Activity assessments: ACs: activity categories; ACS-HDL: high-demand leisure activity section of the Activity Card Sort; IADL: Instrumental Activities of Daily Living; IPAQ: International Physical Activity Questionnaire; IPAQ-AF: the Africa francophone version of the International Physical Activity Questionnaire; IPAQ-LF: International Physical Activity Questionnaire Long Form; IPAQ-SF: International Physical Activity Questionnaire Short Form; IPAQ-S7: International Physical Activity Questionnaire-Short 7 Days; PASE: Physical Activity Scale for the Elderly; PASIPD: The physical activity scale for individuals with physical disabilities; PIEL: Participation in Everyday Life; RAPA: The Rapid Assessment of Physical Activity; SGPALS: Saltin Grimby 6-Level Physical Scale; SIS-PHYSICAL: Physical domain of the

Stroke Impact Scale.

Participation assessments: EMA: Ecological Momentary Assessment; BI: Barthel Index; FAI: Frenchay Activities Index; IPAQ: Impact on Participation and Autonomy Questionnaire; LIFE-H: The Assessment of Life Habits Questionnaire; MBI: modified Barthel Index; NEADL: The Nottingham Extended Activities of Daily Living Questionnaire; RNLI: Reintegration to Normal Living Index; SIS: Stroke Impact Scale; SIS–P: Stroke Impact Scale participation subscale; USER-P: Utrecht Scale for Evaluation of Rehabilitation-Participation; SAM: Step-watch Activity Monitoring; WSAS: Work and Social Adjustment Scale.

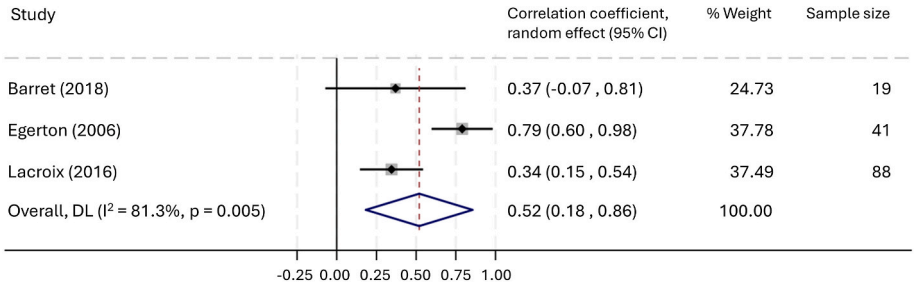


Fig. 2. Pooled correlations between PA (objective devices) and self-reported questionnaires on participation in daily life activities (Barthel Index) in participants within 6 months post-stroke.

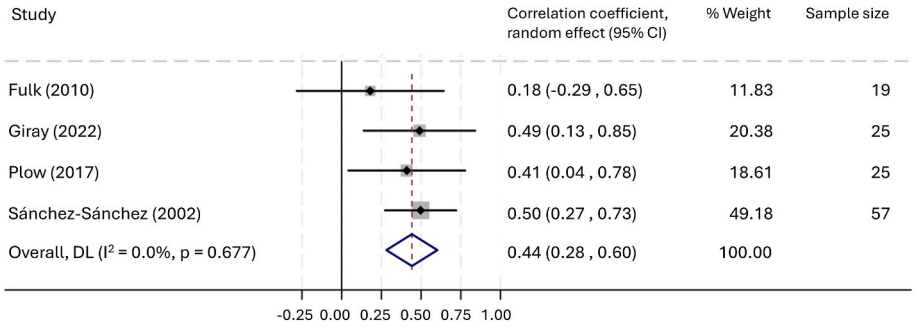


Fig. 3. Pooled correlations between PA (self-reported questionnaires & objective devices) and participation in all areas (Stroke Impact Scale) in participants greater than 6 months post-stroke.

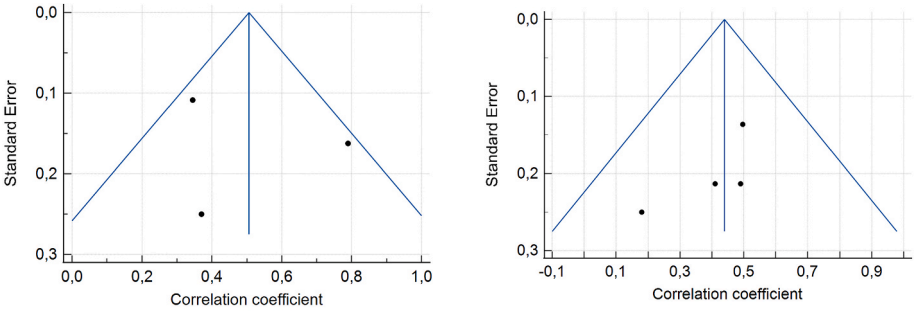


Fig. 4. Funnel plots and Egger's test assessing selection bias in (A) participants within 6 months post-stroke and (B) participants greater than 6 months post-stroke.

4.3. Study limitations

Despite incorporating the available scientific evidence to date, this study could only conduct a meta-analysis with seven studies due to the extensive heterogeneity in variables and assessment across articles, coupled with limited data provided in them. The correlations observed between the variables PA and participation depend directly on the assessment tools used and the impact of the intervention, and it is essential to interpret these findings with caution. Additionally, potential collinearity between variables due to the energy expenditure involved in carrying out any activities of daily living[74] may lead to an overestimation of the correlation[113] and the reader should interpret the results with appropriate caution.

5. Conclusions

This review demonstrated a moderate correlation between PA and participation levels within the first 6 months after stroke, which appears

to persist beyond 6 months. Improvements in PA and participation may require more than 6 months to manifest. Subsequent research is essential to validate these findings and establish a standardized framework for assessment methodology and follow-up times in stroke survivors.

Funding

This work was supported by Universidad San Jorge with the aid "Publicación de artículos en Acceso Abierto - Curso 2023–2024". Authors CDA, JBA, ABE, RGN, MLR, PRP, VDG and PBL are members of the research group MOTUS supported by "Gobierno de Aragón" (n. B60_23D). JBA is supported by the Grant PIF 2022–2026 from "Gobierno de Aragón", Spain. NAF is supported by a National Health and Medical Research Council of Australia Fellowship (grant number: 2026151). The funders did not have any role in this study.

CRediT authorship contribution statement

Cristina de Diego-Alonso: Writing – review & editing, Writing – original draft, Visualization, Resources, Methodology, Investigation, Data curation, Conceptualization. **Pablo Bellosta-López:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Software, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Julia Blasco-Abadía:** Writing – review & editing, Resources, Methodology, Investigation. **Almudena Buesa-Estéllez:** Writing – review & editing, Resources, Methodology, Formal analysis. **Patricia Roldán-Pérez:** Writing – review & editing, Resources, Methodology, Formal analysis. **Almudena Medina-Rincón:** Writing – review & editing, Resources, Data curation. **María Pilar López-Royo:** Writing – review & editing, Resources, Data curation. **Rafael Giner-Nicolás:** Writing – review & editing, Resources, Investigation, Data curation. **Víctor Doménech-García:** Writing – review & editing, Validation, Resources, Funding acquisition. **Natalie A. Fini:** Writing – review & editing, Validation, Supervision, Methodology, Investigation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2024.101640.

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5.2. Validación de herramienta de valoración IPAQ-SF: artículo 2

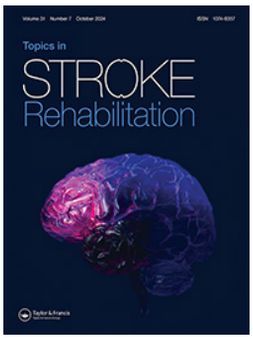
Artículo 2: Validity and stability of the International Physical Activity Questionnaire for stroke survivors with preserved walking ability

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Topics in stroke rehabilitation 2024 Oct 22:1-10
(Editorial: TAYLOR & FRANCIS LTD)
Q1, JIF:2.2
DOI: 10.1080/10749357.2024.2417645.

Citar como: *de Diego-Alonso C, Blasco-Abadía J, Doménech-García V, Bellosta-López P. Validity and stability of the international physical activity questionnaire short-form for stroke survivors with preserved walking ability. Top Stroke Rehabil. 2024 Oct 22:1-10. doi: 10.1080/10749357.2024.2417645. Epub ahead of print. PMID: 39436814.*



Topics in Stroke Rehabilitation

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/ytsr20

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To cite this article: Cristina de Diego-Alonso, Julia Blasco-Abadía, Víctor Doménech-García & Pablo Bellosta-López (22 Oct 2024): Validity and stability of the international physical activity questionnaire short-form for stroke survivors with preserved walking ability, Topics in Stroke Rehabilitation, DOI: 10.1080/10749357.2024.2417645

To link to this article: https://doi.org/10.1080/10749357.2024.2417645

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TOPICS IN STROKE REHABILITATION
https://doi.org/10.1080/10749357.2024.2417645

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Validity and stability of the international physical activity questionnaire short-form for stroke survivors with preserved walking ability

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ABSTRACT

Background: Stroke survivors usually present sedentary lifestyles and fail to comply with the World Health Organization physical activity recommendations. Reliable, low-cost, and fast tools are needed to monitor physical activity levels in this population.

Objectives: This study aimed to evaluate the content and face validity, construct validity, and test-retest stability of the International Physical Activity Questionnaire Short-Form (IPAQ-SF) in stroke survivors.

Methods: One hundred and twenty stroke survivors able to walk independently and preserved comprehension and communication abilities (61 ± 12 years, 35% female) were involved in this psychometric study. Participants completed the interview form of the IPAQ-SF via standardized videoconference twice, one week apart, under identical conditions, to evaluate test-retest stability. Correlations between IPAQ-SF and the caloric expenditure during the minutes of activity registered with the Fitbit Inspire 2 activity tracker wristband and 6-Metre Timed Walk (6MTW) were explored to assess construct validity.

Results: The IPAQ-SF showed good content and face validity. "Moderate" to "strong" correlations were found with the Fitbit Inspire 2 (rho: 0.40 to 0.63), while "weak" to "moderate" correlations were found with the 6MTW (rho: 0.35 to 0.50). Test-retest stability was "moderate" to "excellent" (κ: 0.844 to 0.881; ICC: 0.533 to 0.917).

Conclusions: The IPAQ-SF demonstrated satisfactory content and construct validity, and stability in stroke survivors, supporting its clinical and research utility when the data collection is conducted by trained evaluators using a standardized interview protocol in large samples.

ARTICLE HISTORY
Received 24 May 2024
Accepted 13 October 2024

KEYWORDS
Stroke; questionnaire; physical activity; sedentary behavior; validity; reliability; psychometric properties

Introduction

The World Health Organization (WHO) recommends that adults living with disabilities engage in either 150–300 minutes of moderate-intensity physical activity (MPA) or 75–150 minutes of vigorous-intensity physical activity (VPA) per week or a combination of both (MVPA).[1] It is unquestionable that physical activity (PA) has benefits in primary prevention mitigating cerebrovascular risk factors,[1,2] as well as in secondary prevention and disease treatment.[3] Unfortunately, 33% of the global population remains physically inactive,[1] and this percentage increases to 81% among stroke survivors.[4] Notably, the levels of PA below WHO recommendations are especially detrimental for stroke survivors,[5] as physical inactivity is associated with a 20–30% increased risk of mortality.[2] Conversely, PA serves as a preventive intervention for stroke recurrence and premature mortality,[6] significantly reducing long-term negative consequences such as disability and dependence.[7]

The WHO has pledged to reduce the risk and mortality associated with non-communicable diseases such as stroke. In alignment with this goal, The European Stroke Organization and The Stroke European Alliance launched the Stroke Action Plan for Europe to optimize stroke care across the continent by 2030.[6] One of the key objectives of this plan is to encourage stroke survivors to meet the recommended levels of PA. This challenge requires a comprehensive analysis of the different PA parameters in stroke survivors, such as minutes

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/10749357.2024.2417645

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of MVPA, using valid and reliable methods along with the potential for implementation in both clinical and research settings.

PA levels are assessed using self-reported questionnaires or objective devices such as pedometers, accelerometers, or activity monitoring devices. Nevertheless, self-reported questionnaires are simple and low-cost tools suitable for adults,[5,7,8] which could be valuable in clinical settings if they demonstrate robust psychometric properties. However, despite the availability of several self-reported questionnaires for assessing PA levels, only a limited number have been evaluated for their psychometric properties in stroke survivors.[9] Furthermore, none of these tools can specifically evaluate compliance with the WHO recommendations. In this regard, the International Physical Activity Questionnaire (IPAQ),[10] a commonly used questionnaire for assessing PA levels in adults, has recently been chosen through international consensus to provide data on MVPA time after stroke.[11] The short form (IPAQ-SF) and long form (IPAQ-LF) have equivalent psychometric properties,[12] and facilitate the assessment of compliance with WHO recommendations. Nevertheless, there is a lack of reports on its psychometric properties when used with stroke survivors.[13]

The present study aimed to assess the content and construct validity and the test-retest stability of the IPAQ short-form (IPAQ-SF) over a 7-day period in Spanish stroke survivors who have had a stroke more than 6 months ago were able to walk and preserved cognitive and speech abilities.

Materials and methods

This psychometric study was part of the Part&Sed-Stroke project, a multicentre research initiative on stroke survivors involving 20 collaborating centers from 8 different regions in Spain.[14] The project was conducted per the Helsinki Declaration approved by the Regional Ethics Committee (PI21/333). All participants provided informed consent before enrolling in the study. The present study was elaborated following the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) recommendations.[15]

Participants

All stroke survivors who were receiving or had finished their treatment in rehabilitation centers and hospitals participating in the Part&Sed-Stroke project were recruited from January to December 2023. The inclusion criteria were 1) adults older than 18 years; 2) history of medical diagnosis of stroke for more than 6 months, regardless of its etiology; 3) living at home; 4) have preserved cognitive and speech abilities (i.e. no aphasia and a Mini-Mental Cognitive Test[16] score > 24); and 5) able to walk (i.e. Functional Ambulation Categories ≥ 3). The exclusion criteria were 1) no severe aphasia involving significant alterations in expression or comprehension interfering with data collection; and 2) living in institutions (e.g. nursing homes).

The COSMIN recommendations determined the sample size for calculating construct validity and test-retest properties, considering more than 100 participants to be an excellent sample size.[15] Therefore, after accounting for up to 20% of dropouts, a sample size of 120 participants was intended.

Study measures

Self-reported physical activity

Self-reported PA was evaluated using the interview version of the IPAQ-SF in Spanish, which can be administered via videoconference.[17] The IPAQ is a tool for public use that can be modified without the express authorization of the creators (Creative Commons license "CC BY 4.0") provided that no commercial use is made of it, as is the case here. The IPAQ-SF aims to determine the frequency and time spent on MVPA and walking in the last seven days, as well as the time spent sitting during a weekday as an indicator of time spent in sedentary activity. Activities covered by the IPAQ-SF include leisure-time PA, household and gardening activities, work-related PA, and transport-related PA. The final score is expressed in Metabolic Equivalents of Task (METs) minutes a week (MET-min/week) and categorizes PA levels into Low, Moderate, or High (Table 1).

In order to establish if the equivalent combination of minutes of MVPA throughout the week was below the lowest threshold of the WHO recommendations for adults living with and without disability (i.e. 150

Table 1. Physical activity levels categories according to the international physical activity questionnaire short-form (IPAQ-SF).

– High PA levels criteria achieved when reported one of the following criteria: • ≥3 days of VPA achieving ≥ 1500 METs-min/week. • ≥5 days of any combination of walking and MVPA achieving ≥ 3000 METs-min/week
– Moderate PA levels achieved when reported one of the following criteria: • ≥3 days of VPA achieving ≥20 minutes/day. • ≥5 days of MPA achieving ≥30 minutes/day. • ≥5 days of any combination of walking and MVPA achieving ≥600 METs-min/week
– Low PA levels achieved when no meet the criteria for Moderate or High PA levels

PA: Physical activity; MET: Metabolic Equivalent of Task; VPA: vigorous PA; MPA: moderate PA; MVPA: equivalent combination of moderate and vigorous intensity PA.

minutes of MPA, 75 minutes of VPA, or an equivalent combination of 150 minutes of MVPA),[1] and MVPA minutes were calculated following the formula: MVPA = MPA + (VPA x 2).[18]

Objective physical activity

The activity tracking wristband Fitbit Inspire 2 (*Fitbit, United States, San Francisco, CA*) was used to assess PA level following the recommendations of the international consensus for stroke survivors.[11] The Fitbit wristbands are considered a valid and reliable device for monitoring PA and sleep hours,[19,20] which are considered a valid procedure for stroke survivors.[21]

This device has a 3-axis accelerometry system that allows monitoring of PA parameters. In this study, the average caloric expenditure during the minutes of activity over 7 consecutive days, expressed in kilocalories, was extracted as an indicator of PA.

Walking ability

The walking ability was assessed with 6-Meter Timed Walk (6MTW). For this purpose, the start and end points of the 10 meters as well as the first 2 meters and the last 2 meters were marked on the ground for acceleration and deceleration. The participants were asked to walk 6 meters at a comfortable and consistent speed using their usual support products (e.g. ankle-foot orthosis, walking sticks).[22]

Hypothesis for construct validity

Based on previous studies, it was hypothesized that stroke survivors reporting lower levels of PA would present slower walking speed.[23,24] Likewise, "moderate" to "strong" correlations were expected between the Fitbit Inspire 2 and IPAQ-SF total scores.[25]

Content and face validity

Before starting the data collection, an initial phase was undertaken with 7 professional collaborators (5 physiotherapists and 2 occupational therapists) assessing 7 stroke survivors to validate the content of the IPAQ-SF. The collaborating professionals were trained to unify the administration of the IPAQ-SF questionnaire. Subsequently, group interview sessions were held to review its administration, analyze the data collection process, and collect the peculiarities found when administering it to stroke survivors.[26] Information was collected from both professionals and stroke survivors.

Procedure

Due to the multicentricity of the research project and to standardize the data collection, an external evaluator (the principal researcher – CDA, experimented Occupational Therapist and Physiotherapist) collected data via standardized videoconference. The subjects were assigned to a videoconference by the Microsoft Teams platform (*Microsoft, Redmond, USA*), during which the IPAQ-SF questionnaire was administered according to the instructions in the manual. Furthermore, the 30 collaborating professionals (i.e. 19 physiotherapists and 11 occupational therapists conducting clinical care) were trained in implementing the face-to face assessment protocol for collecting data concerning sociodemographic and clinical characteristics, and the 6MTW scores. All the data were collected and saved through an encrypted data application.[27]

On the first day after enrollment, all participants provided sociodemographic information, and clinical data to the professionals' collaborators by face-to face interview. Each participant was equipped for continuous monitoring with the Fitbit Inspire 2 activity

tracker wristband on the wrist of their least affected arm for a minimum of 7 days. At the end of the session, they completed the Spanish version of the IPAQ-SF by videoconference.

Approximately seven days later, concurrent with a 7-day period of monitoring with the Fitbit Inspire 2, each participant completed the IPAQ-SF for the second time through the same standardized protocol interview to analyze test-retest stability of the IPAQ-SF and assess the construct validity with the Fitbit device. The second interview was conducted on equal conditions to the first day, including any weekly rehabilitation dose received. After the second interview, the professionals' collaborators registered scores in the 6MTW.

Statistical analysis

Data distribution was assessed using the Kolmogorov–Smirnov test. Quantitative variables were expressed as mean and standard deviations (SD) or median and interquartile range (IQR) depending on the data distribution. Categorical variables were expressed as numbers and percentages.

Spearman's rank correlation was used to assess the construct validity for the IPAQ-SF with the Fitbit Inspire 2 and 6MTW. Correlations were considered as strong (rho ≥ 0.60), moderate (0.40 > rho < 0.59), weak (0.20 > rho < 0.39), and negligible (rho ≤ 0.20).[28]

The test-retest stability of categorical variables (i.e. compliance with WHO recommendations and IPAQ-SF categorical scoring) was evaluated by calculating the overall rate of agreement and using the kappa or weighted kappa coefficient. The level of agreement was defined as "*very good*" (κ ≥ 0.81), "*good*" (0.61 ≤ κ ≤ 0.80), "*moderate*" (0.41 ≤ κ ≤ 0.60), "*fair*" (0.21 ≤ κ ≤ 0.40), and "*poor*" (κ ≤ 0.20).[29] Continuous variables (i.e. self-reported PA minutes, MET-min /week, and sitting time) were evaluated for single measurement absolute agreement based on a two-way mixed model by computing intraclass correlation coefficients (ICC). An ICC above 0.90 was considered "*excellent*", 0.75–0.90 "*good*," 0.50–0.75 "*moderate*," and less than 0.50 "*poor*" reliability.[30] One-sample T-tests were used to detect an average bias (i.e. if a systematic error related to the first or the second interview existed).

Statistical analysis was performed using SPSS v.25 (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp), and statistical significance was accepted at $p < 0.050$.

Results

Table 2 presents the sociodemographic and clinical characteristics of 114 out of 120 participants who completed the study. Six participants were unable to attend the second day of assessments. The mean period between the first and second completion of the IPAQ-SF was 7.4 ± 0.3 days [range between 7 and 9 days]. Table 3 presents the self-reported IPAQ-SF scores collected by the same blinded external evaluator at the first and second interviews.

Content and face validity

The key aspects highlighted by collaborating professionals included the challenges faced by stroke survivors in accurately perceiving the time spent on PA and the effort expended. They noted that this could be influenced by factors such as metabolic responses affected by medication, post-stroke effects like fatigue, and sensorimotor alterations or difficulties in cognitive processing (i.e. lack of understanding); identifying that it is a self-reported questionnaire that has not been validated for people with comprehension and communication difficulties. Recognizing these challenges, collaborating professionals found it beneficial to provide examples for both VPA and MPA. Additionally, collaborating professionals emphasized the need to assist individuals in calculating the time spent on each activity. This was particularly important when considering time spent sitting, where they found it useful and necessary to review the day and inquire about the duration of each sitting activity. Finally, collaborating professionals identified misunderstandings when individuals were asked to indicate the time spent walking. It was important to clarify that "walking" referred specifically to ambulating without the aid of a support device such as a walking stick or assistance from another person.

Supplementary material contains a detailed information after the content and face validity phase.

Table 2. Socio demographic and clinical characteristics.

Age (years)	61.4 ± 12.4
Female (n, %)	40, 35%
Height (cm)	167.6 ± 8.3
Weight (kg)	75.6 ± 15.3
Time since stroke (years)	3.5 [1.7 – 6.9]
Stroke type (n, %)	
Hemorrhagic	49, 43%
Ischemic	65, 57%
Stroke hemisphere (n, %)	
Right	65, 57%
Left	45, 40%
Both	4, 3%
Receiving rehabilitation (n, %)	
Yes	99, 87%
No	15, 13%
Gait aid (n, %)	
None	77, 68%
Walking stick	35, 31%
Ankle-foot orthosis	4, 3%
FAC (n, %)	
3	13, 11%
4	28, 25%
5	73, 64%
Fitbit Inspire 2 (kcal during activity)	961 ± 582
6MTW (s)	7.5 [5.3 – 12.3]

N = 114. Data are expressed in Mean ± SD or median [IQR 25–75]. SD: Standard deviation; IQR: Interquartile range; 6MTW: 6-Metre Timed Walk.FAC: Functional ambulation categories

Table 3. International physical activity questionnaire short-form (IPAQ-SF) of participants during the first and second interview.

	First interview	Second interview
Vigorous PA (min*week)	15.4 ± 69.4	14.6 ± 61.4
Moderate PA (min*week)	75.7 ± 150.9	83.4 ± 138.7
MVPA (min*week)	106.6 ± 205.4	108.4 ± 203.9
Walking (min*week)	298.2 ± 255.7	305.7 ± 266.3
Sitting (hours)	6.9 ± 2.9	6.7 ± 2.8
Total (MET-min/week)	1410 ± 1236	1511 ± 1281
IPAQ-SF categories (n, %)		
Low	33, 29%	31, 27%
Moderate	70, 61%	73, 64%
High	11, 10%	10, 9%
WHO recommendations (n, %)		
No	91, 80%	88, 77%
Yes	23, 20%	26, 23%

N = 114. Data are expressed in mean and standard deviation otherwise specified. PA: Physical activity; MVPA: equivalent combination of moderate and vigorous intensity PA; MET: Metabolic Equivalent of Task; WHO: World Health Organization.

Construct validity

The coefficients for the correlations between the IPAQ-SF and the Fitbit Inspire 2 and the 6MTW to assess the construct validity are presented in Table 4.

For caloric expenditure during activity minutes registered with the Fitbit Inspire 2, a "strong" positive correlation was found with the total MET-min/week (rho = 0.63), and "moderate" positive correlations with accumulated minutes per week in MVPA and walking activities combined (rho > 0.40). For the 6MTW, "moderate" positive correlations were found with accumulated minutes in walking activities and total MET-min/week (rho > 0.41).

Test-retest stability

For categorical variables, kappa values indicated a "very good" agreement for compliance with WHO recommendations (agreement: 95%; $\kappa = 0.881$) and IPAQ-SF categorical scoring (agreement: 89%; $\kappa_w = 0.844$).

Table 4. Table of correlations between the international physical activity questionnaire short-form (IPAQ-SF), and the caloric expenditure during the minutes of activity registered with the Fitbit Inspire 2 and the time during the 6-metre timed walk (6MTW).

IPAQ-SF	6MTW	Fitbit Inspire 2
Vigorous PA	0.17	0.28*
Moderate PA	0.31*	0.29*
MVPA	0.35*	0.40*
Walking	0.41*	0.57*
Sitting hours	−0.32*	−0.39*
Total MET	0.50*	0.63*

Data are expressed in terms of Spearman correlation coefficients. PA: Physical activity; MET: Metabolic Equivalent of Task; MVPA: equivalent combination of moderate and vigorous intensity PA. *$p < 0.05$.

Table 5 presents mean differences error, limits of agreement, and ICC of IPAQ-SF continuous variables. The test-retest stability was "excellent" for accumulated minutes per week in total MET-min/week; good for accumulated minutes per week in MPA, equivalent combination of MVPA, and walking activities; and "moderate" for accumulated minutes per week in VPA and sitting time. Any of the outcomes presented an average bias ($p > 0.211$).

Discussion

This study investigated the content and face validity, construct validity, and test-retest stability of the IPAQ-SF in Spanish stroke survivors. The results indicated appropriate content and face validity, construct validity, and "moderate" to "excellent" test-retest stability.

Content and face validity

The IPAQ-SF has been recently suggested as a useful assessment questionnaire to collect information on PA time in stroke survivors.[11] Besides, a previous study highlighted the necessity of investigating this questionnaire's content and face validity.[25] The present study found that providing examples of activities involving VPA and MPA may be appropriate to obtain reliable results. Furthermore, it is important to consider that as a self-reported questionnaire, it is not indicated for people who have communication difficulties, or cognitive impairments. However, it is crucial to administer it with special attention to mitigate retrospective bias.[31] Moreover, the sequelae of stroke, such as fatigue[32] and the perception of the level of PA performed, may influence the types and adaptations in the PA undertaken,[33] as well as their perception of the intensity and duration of PA.[34]

Construct validity and test-retest stability

A recent study with stroke survivors demonstrated the validity of the long version of the IPAQ (IPAQ-LF), showing a "moderate" to "strong" correlation with the ActiGraph GT3X+ accelerometer.[25] Specifically, the IPAQ-LF indicated an excess of MVPA and a deficit of total PA compared to the accelerometer in stroke survivors with the highest levels of PA. Based on these results, the IPAQ-SF was considered a useful tool for screening both highly active and inactive stroke survivors after 6 months from their stroke with high functional capacity who require specific interventions to promote healthy habits. Meanwhile, IPAQ-LF overestimated the time spent in MVPA and underreported the time spent on sedentary behavior compared to the accelerometer.[25] Similar to the findings for the IPAQ-LF,[25] the IPAQ-SF correlated "moderate" with MVPA recorded with an objective device. It even demonstrated a "strong" correlation with the total METs-min/week. These findings suggest that in the absence of objective measurement devices in the clinical context, it is possible to obtain adequate correlated data with objective parameters by administering both the IPAQ-LF and IPAQ-SF in stroke survivors.

Table 5. Test-retest stability values for the international physical activity questionnaire short-form (IPAQ-SF): average bias, limits of agreement, and inter-class correlation (ICC).

	Average bias	Limits of agreement	ICC (95%CI)
Vigorous PA (min*week)	0.8 ± 36.6	−70,9 to 72,5	0.53 (0.09 – 0.76)
Moderate PA (min*week)	26.6 ± 113.1	−195,1 to 248,4	0.78 (0.60 – 0.88)
MVPA (min*week)	28.2 ± 92.5	−153,0 to 209,5	0.89 (0.79 – 0.94)
Walking (min*week)	−58.2 ± 152.1	−356,3 to 239,8	0.79 (0.64 – 0.89)
Sitting (hours)	−0.5 ± 2.3	−5,0 to 3,9	0.66 (0.43 – 0.81)
Total (MET-min/week)	−79 ± 525	−1108 to 950	0.92 (0.85 – 0.96)

PA: Physical activity; MET: Metabolic Equivalent of Task; MVPA: equivalent combination of moderate and vigorous intensity PA.

The "moderate" correlation between self-perceived PA measured with the IPAQ-SF and the walking ability measured with 6MTW reveals that individuals with higher PA levels tend to exhibit a faster walking speed. This may highlight the clinical relevance of influencing walking speed, given its association with sedentary behavior in stroke survivors.[23,24] However, the fact that the correlation was moderate also supports that other factors might influence the level of PA, such as sequelae of the stroke, the years of progression, the environment, and social support.[35–37] Therefore, there is a need for studies that looks at these multifactorial relationships.[38]

Previous research regarding the test-retest of IPAQ-SF among other populations with and without disease showed similar results to the presented study.[39] Furthermore, it indicated that self-reported questionnaires exhibit high test-retest reliability and can detect low activity thresholds.[40] However, this study highlights that the IPAQ-SF demonstrated adequate test-retest stability. Furthermore, the present study employed a high-quality methodological design to mitigate assessment bias, including training and standardization sessions for the interview, along with regular supervision of data collection.[14]

IPAQ-SF as a questionnaire for assessing compliance with WHO recommendations

Other tools, such as the Frenchay Activities Index or the Human Activity Profile, have been recommended for evaluating PA in stroke survivors.[9] However, neither provides information to assess compliance with WHO recommendations. Thus, the IPAQ-SF is considered a clinically useful and optimal tool for stroke survivors.[9] The IPAQ-SF questionnaire can be considered a low-cost, time-efficient resource that can reliably be used to screen for physical inactivity in stroke survivors, collecting the activity performed in blocks of 10 minutes or more and being able to aggregate their results for comparison with the WHO recommendations.

Clinical implications and future perspectives

This research provides pertinent information on the psychometric reliability properties of the IPAQ-SF and contributes to establishing a consensus on recommended assessment tools,[41] particularly those regarding the recording of PA parameters.[5] Defining these PA parameters is crucial for both clinical and research purposes to assess the effects of PA on health,[11] adhere to WHO recommendations, and identify significant predictors of physical inactivity.[42] Furthermore, it is recommended to complement these PA parameters with quantitative and qualitative information to understand the factors influencing PA levels in stroke survivors.

Around 70% of stroke survivors are able to walk,[43] among those 75% of them spend their waking time sitting.[23] Participants of the present study with an adequate functional level according to FAC ≥ 3 and no cognitive or communication impairment were considered part of this subgroup. We found that 77–80% did not meet the WHO recommendations. Future studies should investigate the factors influencing sedentary behavior below the WHO recommended levels in stroke survivors with good functional capacity,[14] as they have the greatest potential to achieve the PA levels proposed by the WHO.

Limitations

This study has some limitations. First, the data only provides results regarding the use of the IPAQ-SF in stroke survivors with high functional capacity who have had a stroke more than 6 months ago and cannot be extrapolated to stroke survivors in an earlier phase or with greater functional sequelae. Besides the error associated with the instrument, test-retest stability may be influenced by meteorological factors or natural variations in weekly PA that could have impacted self-reported PA levels, despite being administered under equal conditions.

Conclusion

The IPAQ-SF is a valid questionnaire for screening the PA levels of stroke survivors with preserved physical and cognitive functionality in both clinical and research contexts. This low-cost and rapidly administered tool appears to be useful as a screening questionnaire for compliance with the MVPA levels recommended by

the WHO and correlated with objective device data.

Acknowledgments

We thank you for your participation in the development of the pilot research to professional collaborators: Inés Cortés Cabeza; Ana Conte Lamenca; Leyre Leceaga Gaztambide; Carina Francisco Salgueiro; Lucía Díez Fuentes; Laura Ares Barge and Beatriz Martín Lamata.

We thank all the Spanish collaborating centers and the collaborating professionals involved for the recruitment of study participants: ADACECO, AENO, AGREDACE, AIDA, ASPAYM, CENNER, CIRON, Clínica de neurorehabilitación, Fundación Pita López, Grupo 5 CIAN Navarra, Grupo 5 CIAN Zaragoza, Hospital Provincial Sagrado Corazón de Jesús, Hospital Universitario San Jorge, INEURO, NEUFIS, NEURAXIS, NEUROESPLUGUES, and Rehabilitación El Carmen, as well as self-employed professionals Lezcano Fisioterapia and Juan Luis Abeledo Alcón.

Collaborators 'Part&Sed-Stroke collaborators' list of names: Alicia, Tornero Navarro; Ana, Conte Lamenca; Andrea, Yerro Astrain; Beatriz, Martín Lamata; Carina, Salgueiro; Claudia, Marín Marín; Diana, Ruiz Ramos; Elena, Sanz Sanza; Enrique, Villa Berges; Fernando, Cuesta Ruiz; Inés, Cortés Cabeza; Javier, Harguindey; Juan Luis, Abeledo Alcón; Laura, Ares Barge; Leyre, Leceaga Gaztambide; Lilian, Le Roux; Lourdes, Martín Gros; Lucía, Díez Fuentes; María Carmen, Grácia Sen; María Pilar, Pardo Sanz; Natalia, Muiño: Paloma, Rodríguez Escudero; Paz Cristina, Sánchez Lecina; Rebeca, Yebra Vilarchao; Sara, Beltrán Roche; Verónica, Montoya Murillo.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was co-funded by "Ayudas a Proyectos Internos de Investigación Universidad San Jorge curso 2021-2022" [grant number 2122037]. Cristina de Diego-Alonso, Julia Blasco-Abadía, Víctor Doménech-García, and Pablo Bellosta-López are supported by Departamento de Ciencia, Universidad y Sociedad del Conocimiento, from the Gobierno de Aragón (Spain) (Research Group MOTUS B60_23D). Julia Blasco-Abadía is a predoctoral research fellow supported by the Grant PIF 2022–2026 from the Gobierno de Aragón (Spain). The open access publication was supported by Universidad San Jorge through the grant 'Publicación de artículos en Acceso Abierto - Curso 2024-2025. The funders did not have any role in this study.

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SUPPLEMENTARY MATERIAL

Supplementary table 1. Synthesis of the feedback collected during the content validity interviews.

Section	IPAQ-SF tool indications and items	Recommendations on further clarifications for stroke survivors in relation to each item	Considerations for the evaluator about stroke survivors and response provided
Explanation of the questionnaire	We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise, or sport.	• They should include all activities performed while awake including the physical activity performed during rehabilitation sessions and participation in activities of daily living (e.g. housework or leisure activities). • It would be advisable to ask beforehand if there is any situation that may have conditioned their level of physical activity over their usual level during the previous 7 days.	• It should be noted that they should answer in reference to the physical activity they have done during the previous 7 days, not what they usually do. The level of physical activity of stroke survivors may be influenced by their emotional state, presence of pain, falls, fatigue, weather conditions or side effects of medications, among others. • Stroke survivors may be physically unfit due to the sequelae of the stroke or their lifestyle. • It is recommended that the questionnaire be administered by professionals with clinical experience in neurological rehabilitation.
Vigorous Physical activity	Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.	• It is important to highlight that it must be 10 or more minutes at a time.	• The perception of the time allocated to the activity can be influenced by the perception of the effort made. The greater the perceived effort, the greater the feeling of time elapsed, especially in physically deconditioned stroke survivors. • The perceived intensity of physical activity may vary from that of people without physical sequelae. Stroke survivors may have a higher energy expenditure and may perceive that they are engaged in strenuous physical activity when they are engaged in activities that for other people involve moderate effort. • The metabolic response (increased heart rate or sweating) to physical activity may differ from healthy people because it is modulated by medication.
	1. During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling? _____ days per week	• Other examples of activity can be provided: e.g. Fast exercise bike, fast elliptical or strength exercises in treatment sessions.	• It should be considered that most stroke survivors do not or cannot perform the activities proposed as examples in the questionnaire. It is necessary to provide other possible examples.

Section	IPAQ-SF tool indications and items	Recommendations on further clarifications for stroke survivors in relation to each item	Considerations for the evaluator about stroke survivors and response provided
	2. How much time did you usually spend doing vigorous physical activities on one of those days? _____ hours per day _____ minutes per day	• It is important to support the calculation of the time spent on physical activity.	• Stroke survivors may have difficulties in processing information, cognitive functions such as mental calculation or expression, and may provide an incorrect answer.
Moderate Physical Activity	Think about all the moderate activities that you did in the last 7 days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.	• It is important to highlight that it must be 10 or more minutes at a time.	• The perception of the time allocated to the activity can be influenced by the perception of the effort made. The greater the perceived effort, the greater the feeling of time elapsed, especially in physically deconditioned stroke survivors. • The perceived intensity of physical activity may vary from that of people without physical sequelae. Stroke survivors may have a higher energy expenditure and perceive that they are moderately physically active when they are engaged in activities that are not strenuous or are lightly strenuous for others. • The metabolic response (increased heart rate or sweating) to physical activity may differ from healthy people because it is modulated by medication.
	3. During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? ____ days per week	• It is important to remember that walking is excluded in this section. • Other examples of activity can be provided: e.g. swimming, exercise bike at a regular pace or adapted sports such as sailing, table tennis.	• The only physical activity that most stroke survivors do is walking. When you tell them that we cannot include this activity in this question, they may feel overwhelmed. It is important to point out that this is relevant, but that it will be taken into account in the following questions.
	4. How much time did you usually spend doing moderate physical activities on one of those days? _____ hours per day _____ minutes per day	• It is important to support the calculation of the time spent on physical activity.	• Stroke survivors may have difficulties in processing information, cognitive functions such as mental calculation or expression, and may provide an incorrect answer.

Section	IPAQ-SF tool indications and items	Recommendations on further clarifications for stroke survivors in relation to each item	Considerations for the evaluator about stroke survivors and response provided
Walking time	Think about the time you spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.	• It is important to highlight that it must be 10 or more minutes at a time.	• Some stroke survivors may mistakenly consider that they are walking when they use their electric wheelchair or are taken for a ride by another person in a manual wheelchair. • Time spent walking both indoors and outdoors with or without assistive products such as canes or crutches or the help or supervision of others is covered. • Some people may consider that it is only time exclusively for changing, not counting time spent going to the supermarket, to drink a coffee, to the rehabilitation centre or time spent walking in the hallway or garden at home.
	5.During the last 7 days, on how many days did you walk for at least 10 minutes at a time? _____ days per week	• They should include all activities performed while awake including the physical activity performed during rehabilitation sessions (e.g., treadmill) and participation in activities of daily living (e.g., shopping in supermarket or leisure activities such as hiking).	• Although their speed is slow, most stroke survivors move from one place to another in more than 10 minutes. It is advisable to provide examples.
	6.How much time did you usually spend walking on one of those days? _____ hours per day _____ minutes per day	• It is important to support the calculation of the time spent on walking.	• Stroke survivors may have difficulties in processing information, cognitive functions such as mental calculation or expression, and may provide an incorrect answer.
Sitting time	The last question is about the time you spent sitting on weekdays during the last 7 days. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.	• It is important to highlight the type of activities that are included in this question.	• It should be noted that this also includes time for naps or travel by car or wheelchair.
	7. During the last 7 days, how much time did you spend sitting on a weekday? _____ hours per day _____ minutes per day	• It is important to support the calculation of the time spent on sitting.	• Stroke survivors may have difficulties in processing information, cognitive functions such as mental calculation or expression, and may provide an incorrect answer. • Awareness of sitting time may be much lower than the reality. It may be helpful to ask them what time they get up and go to bed and to review their activities during the day so that they can indicate how much time they spend sitting down.

5.3. Validación de herramientas de valoración SDO-OB: artículo 3

Artículo 3: Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors

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American Journal of Occupational Therapy 2024 May 1;78(3):7803205050
(Editorial: AMER OCCUPATIONAL THERAPY ASSOC, INC)
Q1, JIF:2.1

DOI: 10.5014/ajot.2024.050454.

Citar como: de Diego-Alonso C, Bellosta-López P, Hultqvist J, Vidaña-Moya L, Eklund M. Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors. Am J Occup Ther. 2024 May 1;78(3):7803205050. doi: 10.5014/ajot.2024.050454. PMID: 38640087.

Research Article

Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors

Cristina de Diego-Alonso, Pablo Bellosta-López, Jenny Hultqvist, Laura Vidaña-Moya, Mona Eklund

Importance: Stroke survivors experience changes in participation level, satisfaction with participation, and participation balance, making it necessary to have a validated tool for their assessment.

Objective: To evaluate the psychometric properties of the Spanish version of the Satisfaction With Daily Occupations and Occupational Balance (SDO–OB) in stroke survivors.

Design: Psychometric study.

Setting: National multicenter study (rehabilitation centers, and hospitals).

Participants: One hundred forty stroke survivors with and without a primary caregiver.

Outcomes and Measures: Participants completed the SDO–OB, the five-level version of the EQ–5D (EQ–5D–5L), and the Activity Card Sort (ACS). Internal consistency, convergent validity, known-groups validity, and floor and ceiling effects were assessed. Intraobserver reliability was assessed 1 wk apart.

Results: The internal consistency was acceptable; Cronbach's $\alpha = .80$, 95% confidence interval (CI) [0.75, 0.85]. A moderate correlation was found between the SDO–OB summed participation level and summed participation satisfaction ($\rho = .53$). Both SDO–OB summed scores correlated with ACS scores ($0.25 < \rho < .61$). However, only summed participation satisfaction scores correlated with the emotional component of the EQ–5D–5L ($\rho = .32$). The SDO–OB discriminated between groups with and without a caregiver ($p = .001$) and had no floor or ceiling effects (<7%). Good intraclass correlation coefficients (ICCs) were obtained for summed participation level (ICC = .91; 95% CI [.85, .94]) and summed participation satisfaction (ICC = .86; 95% CI [.78, .92]). Standard error of measurement and minimum detectable change were 0.7 and 1.9 points, respectively, for summed participation level and 4.5 and 12.4, respectively, for summed participation satisfaction.

Conclusions: The Spanish version of the SDO–OB presented good psychometric properties, making it a suitable instrument to address participation level, participation satisfaction, and participation balance in stroke survivors.

Plain-Language Summary: After a stroke, survivors experience changes in their participation in daily activities and how satisfied they are with them. This study examined whether a tool called Satisfaction With Daily Occupations and Occupational Balance (SDO–OB) could provide reliable information about this. We looked at 140 stroke survivors from different places in Spain to see whether they had someone caring for them, how healthy they were, and how their participation in daily activities changed after stroke. We found that the SDO–OB is helpful for understanding a stroke survivor's situation and can identify areas needing intervention and track changes caused by intervention plans.

de Diego-Alonso, C., Bellosta-López, P., Hultqvist, J., Vidaña-Moya, L., & Eklund, M. (2024). Psychometric properties of the Spanish version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish stroke survivors. *American Journal of Occupational Therapy, 78,* 7803205050. https://doi.org/10.5014/ajot.2024.050454

A stroke is a cerebrovascular disease that is the third leading cause of disability in the world. In 2019, Spain had an incidence of 61,102 cases of people with poststroke sequelae (GBD 2019 Stroke Collaborators, 2021). According to World Health Organization (WHO) projections, one in four people will have a

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stroke throughout their lifetime (GBD 2019 Stroke Collaborators, 2021), leaving sequelae that will generate limitations in daily activities and restrictions in participation for that person (Norlander et al., 2016) and will cause a high cost that will become necessary to reduce through rehabilitation (Della Vecchia et al., 2021).

Previous studies have indicated that social support plays a significant role in predicting community participation among stroke survivors, although stroke survivors face various barriers, including social stigma and their own personal attitudes, which can lead to increased isolation (Elloker & Rhoda, 2018; Shrivastav et al., 2022). However, a high percentage of stroke survivors live at home with substantial support from family members and/or privately employed assistants. Many of these caregivers take on the role of providing assistance when the person is unable to participate on their own. Moreover, some stroke survivors may increase their self-confidence with the help of others, which is necessary to overcome environmental barriers (Bailey, 2019). Despite these factors, the relationship between participation in activities and the presence of a primary caregiver remains underexamined (Hall et al., 2020).

Participation is essential for stroke survivors' well-being and quality of life (Norlander et al., 2018). The term *participation* is included in the *International Classification of Functioning, Disability and Health* (*ICF*) and, together with the term *activity*, consists of nine domains: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, and social and civic life (WHO, 2001). It is a comprehensive concept including various facets such as the range of activity areas in which a person participates, perceived balance in participation, and satisfaction with participation (American Occupational Therapy Association, 2020). It has been observed that participation restrictions involve an important change in the participation balance and satisfaction of stroke survivors (Kassberg et al., 2021; Wagman et al., 2012), and this can lead to participation imbalance (Kassberg et al., 2021).

Adequate assessment tools are crucial for understanding the adjustment process in relation to the participation level, the satisfaction with participation, and the participation balance that occurs through giving up previous participation in activities or incorporating participation in new ones poststroke. Using such tools provides important information about the person's lifestyle and their perception of it, enabling the detection of motivation or resistance to potential changes in their current participation situation. Among the assessment tools that exist in Spanish, those that are most used with this group typically measure activities of daily living, but they do not include satisfaction or the sense of balance that these activities may generate (Tse et al., 2013). Moreover, assessments are often used without considering their psychometric properties, such as adaptation to the Spanish context or their validity for a specific population (Prieto-Botella et al., 2022). Specifically, the participation domain of the Stroke Impact Scale (SIS–P; Mulder et al., 2016), the Assessment of Life Habits Scale (Engel-Yeger et al., 2018) and the Activity Card Sort (ACS; Ezekiel et al., 2019) are the most commonly used participation assessment tools for stroke survivors under the *ICF* framework. However, they do not uniformly cover the nine activity and participation domains of the *ICF*, leading to biased information (Ezekiel et al., 2019), and they may not fully capture the perceived impact of stroke on these domains (Ytterberg et al., 2017). The SIS–P is the only one validated for Spanish stroke survivors (Aguado, 2010).

At present, there is a need for an assessment instrument in Spanish that is validated for stroke survivors and assesses participation level in the broad sense that is operationalized in the *ICF* framework and additionally addresses satisfaction with participation and participation balance (Palstam et al., 2019; Wassenius et al., 2022). One such instrument is the Satisfaction with Daily Occupations and Occupational Balance (SDO–OB; Eklund & Argentzell, 2016). This tool provides a subjective and individualized view of the person regarding restrictions in participation, which is necessary for person-centered health practice (Ezekiel et al., 2019).

The Satisfaction with Daily Occupations (SDO) is a tool that was constructed with the aim of assessing a person's participation level and satisfaction according to four participation areas: work, leisure, home management, and self-care. The SDO was later extended to the SDO–OB, with questions on participation balance for each participation area (Eklund & Argentzell, 2016). In the SDO–OB, participation balance refers to the person's perception of having the right amount and the right variation of activities (Wagman et al., 2012). The SDO was initially validated in various populations with mental health problems in Sweden (Eklund, 2004; Eklund & Gunnarsson, 2008; Eklund & Sandqvist, 2006), but it was also used successfully with people who had been diagnosed with Parkinson's disease (Hultqvist et al., 2020). An Arabic version of the SDO has been validated in a population with neurological conditions, the majority of whom were stroke survivors (Manee et al., 2015), and a Danish version has been validated in a population of asylum seekers (Eklund & Morville, 2014). Furthermore, the SDO–OB was translated and cross-culturally adapted for the Spanish population through a forward- and back-translation process and was subsequently validated in a Spanish population with mental health problems (Vidaña-Moya et al., 2020). However, the Spanish version has not yet been validated for stroke survivors.

Given that there is no validated Spanish assessment tool for a population of stroke survivors that fully covers the domain of participation in activities (Tse et al.,

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2013), including the person's own perspective, developing such tools is an urgent matter (Engel-Yeger et al., 2018). The Spanish version of the SDO–OB (Vidaña-Moya et al., 2020), validated for people with mental illness and those without a known illness, might also be an appropriate tool for stroke survivors. It could provide key data for stroke survivors concerning participation level and satisfaction with participation, and it could give a time allocation perspective on their perceived participation balance. Such information would be vital for setting goals, developing individualized treatment plans, and evaluating results; and, if found psychometrically sound with stroke survivors, the Spanish version of SDO–OB could be used in both clinical practice and research.

In the present study, we aimed to evaluate the psychometric properties (internal consistency, convergent validity, known-group validity, floor and ceiling effects, intraobserver reliability, and measurement error) of the Spanish version of the SDO–OB when used with people who had a stroke more than 6 mo earlier.

Method

This psychometric study was conducted between February and November 2022 as part of the Part&Sed-Stroke project (de Diego-Alonso et al., 2023). It is a multicenter research project focused on a multidimensional analysis of sedentary behavior and participation among Spanish stroke survivors who were followed for up 6 mo after onset, involving 20 collaborating centers throughout Spain. The study was approved by the regional ethics committee on human research (PI21/333), and all participants provided informed consent before enrolling.

Participants

Spanish stroke survivors who were followed up after 6 mo were recruited from several rehabilitation centers, clinics, and hospitals participating in the Part&Sed-Stroke project. In each center, collaborators (physiotherapists and occupational therapists) promoted the research study by means of information sheets. Candidates who met the selection criteria signed the informed consent form. The inclusion criteria were as follows:

- ages 18 yr and older;
- a history of diagnosed stroke for more than 6 mo, regardless of etiology;
- outpatient living at home;
- cognitive and speech ability to complete the pertinent tests and understand the purpose of the research (i.e., no aphasia and a Mini-Mental Cognitive Test score higher than 24; Lobo et al., 1999), double-checked by collaborators and the principal investigator); and
- the ability to use and availability of a mobile phone.

The three exclusion criteria were

- the presence of alterations in comprehension or expression that significantly interfered with data collection,
- residence in institutions (e.g., nursing homes), and
- no commitment to continue with the study.

The sample size was determined on the basis of the recommended ratio of a minimum of 10 to 15 subjects per the number of items in the questionnaire (Anthoine et al., 2014). Missing values of approximately 5% were assumed. Therefore, 140 participants were required.

Sociodemographic and Clinical Data

Sociodemographic data included age, sex, educational level, family situation, and the presence or absence of a principal caregiver. A *principal caregiver* was defined as a person, either a family member or privately employed assistant, who spends more than half of their daily time supporting or caring for the stroke survivor.

Clinical data included the date of stroke; type of stroke; damaged cerebral hemisphere; and the Barthel Index, a scale that measures the level of independence in activities of daily living and is one of the most widely used outcome measures to assess functioning in the context of neurorehabilitation (Prodinger et al., 2017).

Outcome Measures

Health Status

The five-level version of the self-assessed quality of life questionnaire EQ–5D (EQ–5D–5L) was used to assess current health status. Respondents rate their quality of life in relation to mobility, self-care, usual activities, pain and discomfort, and anxiety or depression through five possible response options ranging from 1 (*no limitations or disability*) to 5 (*maximal limitations or disability*). In the second part of the questionnaire, respondents indicate their current health status on a scale ranging from 0 (*worst health status imaginable*) to 100 (*best health status imaginable*). The EQ–5D–5L is a valid and reliable tool for assessing health-related quality of life (Ramos-Goñi et al., 2013), it is also used for people who have had a stroke less than 6 mo previously, and it has been used previously in other studies (de Graaf et al., 2022; Golicki et al., 2015).

Regarding the convergent validity hypothesis, it was expected that participants with higher levels of participation and total satisfaction in the SDO–OB would score higher on perceived level of health (or lower limitations or disability, in the case of the subscales), especially on those items that are directly related to participation in daily activities (Norlander et al., 2018).

Perception of Changes in Participation Level

We used the Spanish version of the ACS to assess changes in participation. Of the nine domains defined by the *ICF* (WHO, 2001), the ACS covers eight, further compiled into four participation areas encompassing 20 instrumental activities, 35 leisure activities

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with low physical demand, 17 leisure activities with high physical demand, and 17 social activities. Photographs (i.e., cards) reflecting these daily activities were shown to the respondents, who indicated whether they participated in the activities before the onset of their illness. After viewing the photographs that depicted daily activities, respondents indicated whether they currently maintained their participation at the same level, decreased their participation, or stopped participating altogether. The final score, expressed as a percentage, combines the four participation areas, reveals the overall level of engagement in activities, and shows whether there have been any discontinuations in participation. The ACS is a reliable and validated tool for measuring the perceived level of participation in a Spanish population (Alegre-Muelas et al., 2019), and it has been used previously in stroke survivors after the first 6 mo (Hartman-Maeir et al., 2007).

Regarding the convergent validity hypothesis, it was expected that participants with higher total participation levels according to the SDO–OB would have higher percentages of maintained participation, indicating less change after stroke according to the ACS. Finding such a correlation with the total sum of satisfaction with participation was, however, not expected, because people with low levels of participation may present high levels of satisfaction that are due to resilience and a process of acceptance of the new situation after stroke (Sarre et al., 2014).

Participation Level, Degree of Satisfaction With Participation, and Participation Balance

Participation level, degree of satisfaction with participation, and participation balance among activities were assessed with the Spanish version of the SDO–OB (Vidaña-Moya et al., 2020), an interview-based instrument addressing 13 different everyday activities, organized into four areas: work, leisure, home management, and self-care. With a structured interview format, the SDO–OB is used to assess the level of participation, the satisfaction derived from engaging in this participation, and the perceived participation balance, including the perceived time allocation (if you do too little, just enough, or too much) within each area. For each item, the respondent indicates whether they have recently participated or not (yes–no) and provides a self-rating in relation to the degree of satisfaction with that situation ranging from 1 (*being extremely dissatisfied*) to 7 (*being extremely satisfied*). Yes responses were summed into a participation level score, and the satisfaction ratings were summed to form the satisfaction with participation score. The participation balance scores were rated for each area to assess whether the respondent performed enough, too much, or too little of the activities belonging to that area. Five responses were considered: way too little (–2), too little (–1), just enough (0), too much (1), and way too much (2) (Vidaña-Moya et al., 2020). The SDO–OB also included an overall item regarding general participation balance that uses the same response alternatives. Furthermore, following previous recommendations (Eklund & Argentzell, 2016), we grouped the scores for further analysis as underoccupied (score = –2 or –1), in balance (score = 0), and overoccupied (score = 1 or 2).

Procedure

Before data collection, we conducted a pilot study with 10 stroke patients and 10 professional collaborators. To assess content validity, we interviewed stroke survivors and professional collaborators on the clarity and comprehension of each SDO–OB question and answer type. There were no documented concerns or challenges with the clarity and comprehension of the questions and type of responses of the scale.

During data collection, all participants answered questions on sociodemographic information, clinical history, Barthel Index, the EQ–5D–5L, and the ACS. Participants were classified for further analysis according to the presence of a principal caregiver. Furthermore, according to COSMIN criteria (Mokkink et al., 2010), which considers 50 to 99 participants as an adequate sample for reliability calculations, a subset of 70 participants was randomly selected to complete the Spanish version of the SDO-OB again 1 wk later with the same assessor to analyze intraobserver reliability.

Two circumstances warranted that face-to-face interviews were chosen for the data collection. First, some of the instruments used to collect data, such as the ACS and the SDO–OB, require this. Second, a large number of variables were collected in the Part&Sed-Stroke project. Face-to-face interviews allowed for monitoring the participants; splitting the data collection on several occasions, if necessary; and, thus, avoiding saturating them or losing their concentration. In contrast, clinical data and scores based on the Spanish version of the SDO–OB were collected by a single-blind evaluator who was trained in the administration of the Spanish version of the SDO–OB, with no clinical link to the participants to avoid intraobserver bias (Cristina de Diego-Alonso, an occupational therapist and physiotherapist with 15 yr of experience in treating neurological patients) by videoconference. Collaborators were supervised by the research team and shared the data collected through an encrypted data application (Bellosta-López et al., 2021).

Statistical Analysis

Data distribution was assessed using the Kolmogorov–Smirnov test. Quantitative variables were expressed as median and interquartile range (IQR) or mean and standard deviation (*SD*), depending on the data distribution. Categorical variables were expressed as numbers and percentages.

The internal consistency of the Spanish version of the SDO–OB satisfaction items was assessed with the

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Cronbach's α and corrected item–total correlations (CITCs). A Cronbach's α higher than .7 (Tavakol & Dennick, 2011) and a CITC higher than .3 (Terwee et al., 2007) were considered acceptable.

Convergent validity was assessed with the Spearman's rank correlation. Correlations were calculated between the summed scores of the Spanish version of the SDO–OB (i.e., participation level and satisfaction level, respectively) and the EQ–5D–5L, ACS, and a question (general satisfaction with daily activities) used in the original Spanish validation (Vidaña-Moya et al., 2020). Correlations were considered as strong ($\rho \geq .70$), moderate ($.40 > \rho < .69$), weak ($.10 > \rho < .39$), or negligible ($\rho < .10$; Akoglu, 2018).

We assessed known-groups validity for the summed scores by using the Mann–Whitney *U* test to compare participants who received daily support from a principal caregiver with those who did not. In addition, χ^2 tests were used to compare the participation balance scores.

The test–retest reliability of the Spanish version of the SDO–OB summed scores (i.e., participation level and satisfaction level) was assessed for single measurement absolute agreement, on the basis of a two-way random model, by computing intraclass correlation coefficients ($ICCs_{2,1}$). ICCs above .90 were considered excellent; ICCs of 0.75 to .90, good; ICCs of .50 to .75, moderate; and ICCs less than .50, poor reliability (Koo & Li, 2016).

We calculated the standard error of measurement (*SEM*) and the minimum detectable change (MDC) at 95%. The *SEM*—representing the expected random score variation when no real change has happened in a single person—was calculated with the following formula: $SEM = SDpooled \times \sqrt{(1 - ICC)}$ (Furlan & Sterr, 2018). The MDC—representing the minimal change needed for being a real change rather than a random measurement error in a sample—was calculated with the following formula: $MDC = SEM \times \sqrt{2} \times 1.96$ (Furlan & Sterr, 2018). For the participation balance scores, the overall rate of agreement was calculated, and the weighted κ correlation coefficient was used to assess item response stability after 1 wk. The association was defined as very good ($.81 \leq \kappa \leq 1.0$), good ($.61 \leq \kappa \leq .80$), moderate ($.41 \leq \kappa \leq .60$), fair ($.21 \leq \kappa \leq .40$), or poor ($.00 \leq \kappa \leq .20$; Cohen, 1960).

Fewer than 15% of the respondents achieving the lowest or highest scores were set as criteria for an absence of floor or ceiling effects, respectively (Terwee et al., 2007).

Statistical analysis was performed using IBM SPSS Statistics (Version 28), and statistical significance was accepted at $p < .05$.

Results

Participant Characteristics

Of the 140 participants recruited for the study, 128 provided full data and were included in the analysis. A total of 68 out of the 70 participants who were randomly selected to assess the test–retest reliability completed the Spanish version of the SDO–OB a second time 1 wk after analysis ($M = 7.2$, $SD = 0.2$ days). Sociodemographic and clinical characteristics are presented in Table 1.

Internal Consistency

The internal consistency was acceptable with a Cronbach's α of .80; 95% confidence interval [CI] [0.75, 0.85]. The CITCs had a mean of .44 and ranged between .28 and .55. Table 2 shows the CITCs and Cronbach's α if an item was deleted.

Convergent Validity

Summed scores for participation level and participation satisfaction that were based on the Spanish version of the SDO–OB correlated moderately ($\rho = .53$, $p < .001$). Correlations from these two variables to general participation satisfaction were weak ($\rho = .33$, $p < .001$) and moderate ($\rho = .54$, $p < .001$). There were weak negative correlations with the EQ–5D–5L mobility, self-care, and daily activity components ($\rho = -.20$ to -0.30, $p < .022$) and weak positive correlations with the EQ–5D–5L current health status component ($\rho = .23$ to $.37$, $p < .008$). In addition, the summed participation satisfaction scores had a weak negative correlation with the anxiety and depression component ($\rho = -0.32$, $p < .001$). All ACS participation areas had a moderate positive correlation with both of the SDO–OB summed scores ($\rho = .40$–$.61$,

Table 1. Sociodemographic and Clinical Data of Participants

Sociodemographic Variables	*n* (%)
Age (yr), *M* (*SD*)	61.8 (12.4)
Female	47 (37)
Living alone	19 (15)
Principal caregiver	68 (53)
Study level	
No schooling	3 (2)
Primary studies	27 (21)
Secondary studies	54 (42)
University studies	44 (34)
Time since stroke (yr), *Mdn* (IQR)	3.5 (1.7–7.0)
Stroke type	
Hemorrhagic	56 (44)
Ischemic	72 (56)
Stroke hemisphere	
Right	75 (59)
Left	48 (37)
Both	5 (4)
Barthel Index (0–100), *M* (*SD*)	85.4 ± 17.6

Note. $N = 128$. IQR = interquartile range.

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Table 2. Corrected Item–Total Correlation and α Value if Item Is Deleted

Item	Corrected Item–Total Correlation	Cronbach's α if Item Is Deleted
Satisfaction with work	.46	.79
Satisfaction working the past 2 mo	.47	.79
Satisfaction with rehabilitation	.39	.79
Satisfaction with organized hobby	.55	.78
Satisfaction with hobby on independent basis	.39	.80
Satisfaction with cultural activities	.42	.79
Satisfaction with housework	.50	.79
Satisfaction with repair or maintenance jobs	.38	.80
Satisfaction with planning and organizing of the housework	.49	.79
Satisfaction with care of children, parents, or significant others	.28	.80
Satisfaction with daily self-care	.51	.79
Satisfaction with physical exercise	.37	.80
Satisfaction with rest, relaxation, or recharging their batteries	.48	.79

$p < .001$), except for leisure, which showed a weak positive correlation with both ($\rho = .25$–$.39$, $p < .006$). The correlation coefficients of summed participation level and summed participation satisfaction scores with the variables selected to assess convergent validity are presented in Table 3.

Known-Groups Validity

The discriminating ability of the Spanish version of the SDO–OB was evaluated by comparing participants who were stroke survivors with and without a principal caregiver. The group with a principal caregiver showed lower summed scores for participation level (Mann–Whitney $U = 5.675$, $p < .001$) and lower summed scores for participation satisfaction (Mann–Whitney $U = 3.452$, $p = .001$) than the group without a principal caregiver. Furthermore, the group with a principal caregiver was shown to be underoccupied compared with those without a principal caregiver with regard to home management, $\chi^2(2) = 19.3$, $p < .001$, and general participation balance, $\chi^2(2) = 14.2$, $p = .001$. Descriptive statistics are shown in Table 4.

Table 3. Correlations Between Measures Used to Assess Convergent Validity and SDO–OB Scores

	Correlations for Summed Scores	
Measure	SDO–OB Participation Level	SDO–OB Satisfaction With Participation
General participation satisfaction	.33*	.54*
EQ–5D–5L		
Mobility	−.20*	−.25*
Self-care	−.26*	−.27*
Daily activities	−.24*	−.30*
Pain	−.06	−.15
Anxiety and depression	−.15	−.32*
Current health status	.23*	.37*
ACS		
Instrumental	.61*	.40*
Leisure	.39*	.25*
Social	.45*	.44*
Total	.53*	.41*

Note. Data are expressed in Spearman correlation coefficient. ACS = Activity Card Sort; EQ–5D–5L = five-level version of the EQ–5D; SDO–OB = Satisfaction with Daily Occupations and Occupational Balance.
*$p < .05$.

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Intraobserver Reliability

The test–retest reliability was good for summed participation level (ICC = .91; 95% CI [.85, .94]) and summed participation satisfaction (ICC = .86; 95% CI [.78, .92]) scores. The test–retest reliability for the participation balance scores was good for work (agreement: 78%; κ = 0.69) and home management (agreement: 54%; κ = 0.64), moderate for self-management (agreement: 46%; κ = 0.46), and fair for leisure (agreement: 44%; κ = 0.33) and the general item (agreement: 41%; κ = 0.30).

Measurement Error

For the summed participation level scores, *SEM* and MDC were 0.7 and 1.9 points, respectively. For the summed participation satisfaction scores, the *SEM* was 4.5 points, and the MDC was 12.4 points.

Floor and Ceiling Effects

The analyses of the distribution of frequencies regarding summed participation level and satisfaction scores showed that 7% of the respondents achieved the lowest or the highest scores, indicating an absence of floor or ceiling effects.

Discussion

In this study, we aimed to evaluate the psychometric properties (internal consistency, convergent validity, known-groups validity, floor and ceiling effects, intraobserver reliability, and measurement error) of the Spanish version of the SDO–OB in people who had experienced a stroke more than 6 mo previously. The analyses of data from a large sample showed acceptable internal consistency. There was a moderate correlation between participation level and participation

Table 4. Scores for Summed Participation Level, Summed Satisfaction With Participation, and Participation Balance Scores for Participants With and Without a Principal Caregiver

Variable	*n* (%)		*p*
	Group 1: Participants With Caregiver (*n* = 68)	Group 2: Participants Without Caregiver (*n* = 60)	
Summed participation level score (0–13), *Mdn* [IQR]	5 [3–7]	8 [6–9]	<.001*
Summed satisfaction with participation score (13–91), *Mdn* [IQR]	67 [54–74]	74 [67–80]	.001*
Participation balance area			
Work			
Underoccupied	61 (90)	50 (83)	.493†
In balance	4 (6)	7 (12)	
Overoccupied	3 (4)	3 (5)	
Leisure			
Underoccupied	20 (29)	17 (28)	.299†
In balance	30 (43)	19 (32)	
Overoccupied	19 (28)	24 (40)	
Home management			
Underoccupied	54 (79)	25 (42)	<.001†
In balance	10 (15)	26 (43)	
Overoccupied	4 (6)	9 (15)	
Self-care			
Underoccupied	21 (31)	11 (18)	0.221†
In balance	32 (47)	36 (60)	
Overoccupied	15 (22)	13 (22)	
General			
Underoccupied	32 (47)	12 (20)	0.001†
In balance	29 (43)	29 (48)	
Overoccupied	7 (10)	19 (32)	

Note. IQR = interquartile range.
**p* after the Mann–Whitney *U* test.
†*p* after the chi-square test.

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satisfaction, and both correlated only with those EQ–5D–5L and ACS items that assess the corresponding constructs, indicating acceptable convergent validity. Furthermore, the results showed that the Spanish version of the SDO–OB can discriminate between stroke survivors with a caregiver and those without a caregiver (i.e., known-groups validity). Moreover, the results showed an absence of any floor or ceiling effects, as well as good intraobserver reliability.

Internal Consistency

This study showed that the Spanish version of the SDO–OB has an acceptable internal consistency, which is in line with the Spanish study conducted with people with mental health problems, in which a Cronbach's α of .75 and a mean CITC of .38 were obtained (Vidaña-Moya et al., 2020). This acceptable internal consistency indicates that the 13 items of the SDO–OB, grouped into four areas (work, leisure, home management, and self-care), homogeneously cover the participation construct and provide comprehensive information. Together with the consistent pattern of correlations with the ASC scores, which reflect participation according to the *ICF* (American Occupational Therapy Association, 2020; WHO, 2001), these findings suggest that the SDO–OB may provide a broad perspective on participation, compared with most tools used until now (Engel-Yeger et al., 2018; Ezekiel et al., 2019; Magasi & Post, 2010; Prieto-Botella et al., 2022; Tse et al., 2013).

Convergent Validity

Summed scores for participation satisfaction and participation level demonstrated a moderate correlation, which is similar to the findings of the Spanish validation study of the SDO–OB for mental health (ρ = .521; Vidaña-Moya et al., 2020). Accordingly, the higher the level of participation, the higher the satisfaction, and vice versa. Possibly, interventions focused on increasing levels of participation could start an upward spiral that leads to an increase in levels of satisfaction, in turn, promoting continued and increased levels of participation, again leading to increased satisfaction (Dfarhud et al., 2014). Although this is something that needs to be empirically investigated, it has some support in that participation level has been found to be associated with the perception of recovery among stroke survivors (Ezekiel et al., 2019).

To our knowledge, this is the first SDO–OB study to analyze convergent validity using the EQ–5D–5L and the ACS. Weak correlations were found between the EQ–5D–5L and summed level of participation and summed participation satisfaction scores. The correlation was negative for mobility, self-care and daily activities and for anxiety and depression, whereas it was positive for the global level of health to date. The negative correlation between the level of satisfaction and the level of anxiety and depression may be of particular interest, because, according to the WHO in 2030, counteracting anxiety and depression is one of the objectives to be achieved by people who need rehabilitation (Gimigliano & Negrini, 2017), including people who had a stroke (Norrving et al., 2018). These findings confirm our hypothesis that the levels of participation and satisfaction are reflected in the level of self-perceived quality of life, although they also suggest that participation and quality of life are partly separate phenomena.

Furthermore, a positive correlation was found between the level of participation maintained after the stroke measured with the ACS and the summed participation level scores from the SDO–OB. In relation to our hypothesis, the results confirmed that participants who had experienced a lower percentage of change in relation to their prestroke level of participation according to the ACS were those who had higher levels of participation as measured by the SDO–OB. However, a low correlation was found between both summed participation level and summed satisfaction with participation and ACS leisure. This result may be due to the fact that the domain of leisure is only one of several facets in the summed SDO–OB.

According to the prior hypothesis, no relationship was expected between participation maintained measured with ACS and the SDO–OB satisfaction score. However, our findings revealed moderate correlations between the two variables, indicating a potential association between the level of participation and satisfaction with participation. It is important to note that correlation does not imply causality, and further research is needed to understand the nature of this relationship fully. These results suggest that other factors, such as individual lifestyle and health status, may play a role in the interplay between participation maintained and satisfaction with participation (Sarre et al., 2014).

Known-Groups Validity

Although previous studies have demonstrated the ability of the SDO–OB to discriminate between healthy participants and Spanish people with mental health problems (Vidaña-Moya et al., 2020), Arabic stroke survivors (Manee et al., 2015), asylum seekers in Denmark (Eklund & Morville, 2014), and Swedish elderly people inside and outside the health services (Hultqvist et al., 2017), to our knowledge, this is the first study to demonstrate the instrument's ability to discriminate within a group of Spanish stroke survivors by discerning whether they needed the support of a caregiver. Further studies are needed to understand why participants who had a caregiver had lower levels of participation and satisfaction and an underoccupied situation in relation to participation balance.

Intraobserver Reliability and Measurement Error

Good intraobserver reliability was found, which indicates the stability of the responses to the SDO–OB

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when the same evaluator collects them. Moreover, future SDO–OB users may benefit from the identified *SEM* and MDC cutoffs. They would be of great clinical and research relevance for understanding the impact of interventions or other conditioning factors, especially because previous psychometric studies of the SDO–OB did not investigate these properties (Eklund & Morville, 2014; Hultqvist et al., 2017, 2020; Manee et al., 2015; Vidaña-Moya et al., 2020).

Usefulness of the Satisfaction With Daily Occupations and Occupational Balance

On the basis of the present findings, this study proposes the use of the Spanish version of the SDO–OB as a reference tool in the stroke survivor population in both clinical and research settings, because it meets the needs expressed in previous studies (Engel-Yeger et al., 2018; Tse et al., 2013). The Spanish version of the SDO–OB showed psychometric properties that are similar to those of the most widely used tools for the construct of participation. It covers the nine domains listed in the *ICF* framework and provides, through an interview, information about the level of participation, satisfaction with participation, and participation balance. Although not included in the present study, the SDO–OB can be used to retrieve qualitative information on the basis of the person's perception of the barriers and facilitators that condition participation (Flokén et al., 2016). Therefore, the widespread use of this tool could help to reduce the heterogeneity among the wide range of tools that measure participation in activities in terms of data provided, forms of administration, and quality of psychometric properties (Eyssen et al., 2011), allowing comparison in clinical and research settings.

Needs for Further Research

Future studies should continue to analyze the properties of this tool, such as interobserver reliability and responsiveness. In addition, upcoming research should focus on a qualitative analysis of the information collected by the Spanish version of the SDO–OB in the stroke survivor population to understand the causes that impede their return to participation and identify factors that may help restore their participation situation, in terms of level, satisfaction with participation, and participation balance.

Including the Spanish version of the SDO–OB in future research with stroke survivors may increase the methodological quality of the tools used and thereby provide relevant information on the impact of interventions or natural development, increasing the scarce consistent evidence to date.

Strengths and Limitations

The methodological design of the study reduced intra- and interobserver biases by having a single-blind evaluator trained in administering the Spanish version of the SDO–OB with no clinical link to the participants. In addition, the study had an extensive sample that included a variety of sociodemographic characteristics, which strengthens both internal and external validity. However, selection criteria excluded those populations to whom it could not be administered because of their clinical situation, such as low cognitive functions and language difficulties affecting expression or comprehension.

Implications for Occupational Therapy Practice and Education

The findings of this study have the following implications for occupational therapy practice and education:

- After experiencing a stroke, it is necessary to regain a balanced level of participation in all areas of human occupation.
- The SDO–OB is a simple assessment tool to collect relevant information on the participation of stroke survivors and their satisfaction with that situation.
- The SDO–OB is able to detect changes in the level of participation and satisfaction of stroke survivors, which is of great importance when occupational therapists evaluate their interventions.

Conclusion

The results of the present study provide support for the use of the Spanish version of the SDO–OB as a reference tool in both clinical and research settings where stroke survivors are the target group to record their participation level, satisfaction with participation, and participation balance.

Acknowledgments

We thank all the Spanish collaborating centers and the collaborating professionals involved for the recruitment of study participants: Asociación de Dano Cerebral da Coruña, Asociación de Enfermos Neurológicos Oscense, Asociación de Daño Cerebral Adquirido de Granada, Asociación de Ictus de Aragón, Asociación de personas con lesión medular y otras discapacidades físicas, Centro de Neuro-Rehabilitación, Nutrición y Fisioterapia, Centro Integral de Rehabilitación, Grupo 5 Centro Integral de Atención Neurorehabilitadora Navarra, Neurorrehabilitación y Atención al Neurodesarrollo, Centro de Fisioterapia y Neurorrehabilitación, Rehabilitación Neurológica y Desarrollo Infantil, Centre de Rehabilitació Neurològic, and Rehabilitación El Carmen, as well as self-employed professionals Lezcano Fisioterapia and Juan Luis Abeledo Alcón.

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5.4. Estudio transversal: artículo 4

Artículo 4: Correlational study between physical activity levels and participation in high-functioning stroke survivors.

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Enviado a la revista XXX.
(Editorial: XX)
Q1, JIF:XX

5.5. Estudio cualitativo sobre la actividad y ejercicio físico: artículo 5

Artículo 5: "More than effort, it's dedicating time and perseverance." Experiences of physical activity and physical exercise in stroke survivor with high functional capacity: A qualitative study.

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Disability and Rehabilitation 2024 Nov 25:1-9
(Editorial: TAYLOR & FRANCIS LTD).
Q1, JIF:2.1
DOI: 10.1080/09638288.2024.2429753

Citar como: de Diego-Alonso C, Buesa-Estéllez A, Roldán-Pérez P, Bellosta-López P, Güeita-Rodríguez J. "More than effort, it's dedicating time and perseverance." experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study. Disabil Rehabil. 2024 Nov 25:1-9. doi: 10.1080/09638288.2024.2429753. Epub ahead of print. PMID: 39587442.



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Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/idre20

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To cite this article: Cristina de Diego-Alonso, Almudena Buesa-Estéllez, Patricia Roldán-Pérez, Pablo Bellosta-López & Javier Güeita-Rodríguez (25 Nov 2024): “More than effort, it’s dedicating time and perseverance.” experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study, Disability and Rehabilitation, DOI: 10.1080/09638288.2024.2429753

To link to this article: https://doi.org/10.1080/09638288.2024.2429753

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DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2024.2429753

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RESEARCH ARTICLE

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"More than effort, it's dedicating time and perseverance." experiences of physical activity and physical exercise in stroke survivor with high functional capacity: a qualitative study

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ABSTRACT

Background: Stroke survivors exhibit sedentary behavior, and many do not engage in physical activity and exercise for a number of reasons. Secondary prevention through physical activity is a priority to avoid a new stroke or disease.

Objective: To describe the experience of stroke survivors with maintained walking ability living in Spain regarding physical activity and exercise.

Methods: A qualitative phenomenological study was conducted. Purposive sampling was carried out to include 35 stroke survivors who had stroke more than 6 months ago from 14 neurorehabilitation centers in 24 cities in Spain. Data were collected through semi-structured interviews and researchers' field notes. The Giorgi approach was used for the qualitative analysis of the data collected.

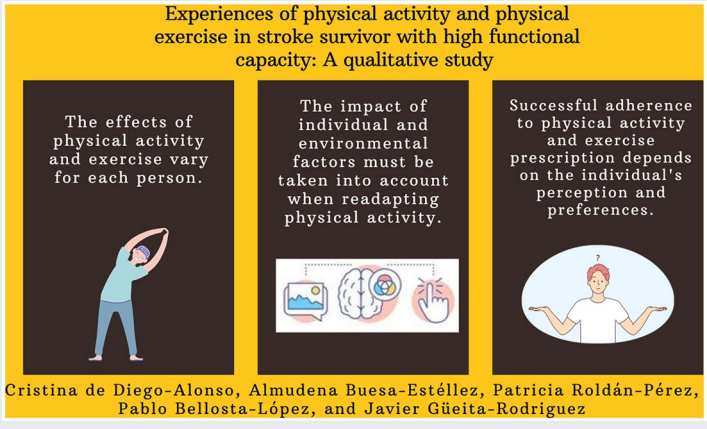
Results: Three themes emerged: a) Changes in the experience of physical activity and exercise adaptation; b) Reasons for and against the practice of physical activity and exercise; c) Experiencing tiredness and fatigue.

Conclusions: Our results show the individual post-stroke perception of each person, the reasons for and against the practice of physical activity and exercise, as well as the impact this has on their daily life and activity. These results will help health professionals to understand the needs of stroke survivors when prescribing physical activity and exercise included in intervention programs.

KEYWORDS

Exercise; physical activity; qualitative research; sedentary behavior; stroke

GRAPHICAL ABSTRACT



IMPLICATIONS FOR REHABILITATION

- Previous experience and the current situation impact individually on the performance of physical activity and exercise in each stroke survivor.
- The influence of individual and environmental factors must be considered in the readaptation of physical activity after a stroke.
- Successful adherence to physical activity and exercise in stroke survivors, requires knowledge of the individual's perception and preferences.
- Physical activity needs to be adapted to the multifactorial background and progression of stroke survivors, ambulation being a suitable approach.

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2024.2429753.
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Introduction

Physical activity (PA) is defined as any bodily movement produced by skeletal muscles that results in energy expenditure that can be measured in kilocalories and can be classified as occupational, sports, fitness, household or other. Likewise, Physical Exercise (PE) is a subset of planned, structured, repetitive PA with the ultimate or intermediate goal of improving or maintaining physical fitness [1].

Stroke survivors exhibit a poor level of PA and sedentary behavior [2], which implies not reaching the PA levels recommended by the World Health Organization (WHO) [3]. However, little is known about the conceptualization and categorization made by stroke survivors in relation to the PA involved during the performance of daily activities and the factors that may influence this perception and efforts to adapt. Previous research shows that some stroke survivors associate intense PA with PE, and just little associate it with the performance of daily life activities (e.g., self-care or housework) [4].

Qualitative studies among stroke survivors reveal diverse preferences in PE and daily activities chosen by patients [4], influenced by varying levels of capacity, opportunities, and motivation [5]. The complexity of the reasons related to this sedentary behavior are multifactorial [5]. Most qualitative studies on stroke survivors have focused on fatigue [6], physical disabilities [7], or the barriers and facilitators to PA participation particularly in those with a sedentary lifestyle [8,9]. However, little is known about the experiences of stroke survivors with mild sequeale who are able to ambulate and may lead a less sedentary lifestyle.

To date, no qualitative study has described the experience of how PA and PE characteristics are modified in stroke survivors in Spain and the adaptations this entails in their lives, especially those preserved functional walking ability and without impaired comprehension and communication after at least 6 months post-stroke. This subgroup, often overlooked in research, holds significant potential within the healthcare system to actively engage in adopting healthy lifestyles, thereby reducing the risk of stroke recurrence [10,11]. Research into their lived experiences is needed to inform the development of individualized intervention plans.

The aim of this study was to describe the experience of stroke survivors with high functional capacity in Spain concerning their PA and PE habits and preferences, exploring the influence of the environment and the individual to understand their reasons for undertaking and adhering to PA and PE.

Methods

This study presents the results of a qualitative research study, included as part of the multicenter Part&Sed-Stroke project [12] designed to examine the multifactorial interaction between PA and participation in everyday life of Spanish stroke survivors over 6 months ago, able to walk who live in their own home and presenting a high functional level when meeting the eligibility criteria described below.

A phenomenological study was carried out [13] based on Husserl's framework [14] to explore the essence of stroke survivors' lived experience using their first-person narratives regarding PA after stroke. In the field of qualitative studies, phenomenology seeks to gain an understanding of the lived experiences of other people in specific circumstances [13] such as therapeutic interventions or health habits [14]. The aim of phenomenology is to study the phenomena as they appear, in order to arrive at an essential understanding of human experience [15].

Research team and reflexivity

Five researchers (2 occupational therapist and physiotherapist and 3 physiotherapists) participated in this research, with an average of more than 10 years of experience working with people with neurologic pathology. All the investigators had experience in health sciences research. ABE, JGR, PRP, PBL were PhD and CDA was a PhD student. Specifically, ABE and JG had more than 10 years qualitative research experience and PBL had extensive experience on methodological research designs as well. CDA had received training in qualitative research and was supervised by ABE and JGR during the conduct of this study. None of them had a clinical relationship with the participants at the time of the study.

Regarding the reflexivity strategies, a bracketing process was carried out prior to the study. Continuously throughout the rest of the phases, the positioning of the research team was established through an intense collaboration among them with scheduled meetings to share the project development, as well as to triangulate during the different stages of the analysis and drafting of the results [16].

Participants and sampling strategies

Stroke survivors participating in this qualitative study were recruited from the Part&Sed-Stroke project [12] with a sample of 140 subjects. Participants were identified and recruited from 14 specialized stroke rehabilitation centers from 24 different cities throughout Spain. The participating centers were associations and private institutions where participants attended on an outpatient basis one or several times a week to receive individualized treatment sessions specialized in neurological rehabilitation (physiotherapy, occupational therapy, neuropsychology or speech therapy). According to the purposive sampling and applying the inclusion criteria described below, the sample participating in this qualitative study was recruited.

In phenomenological studies, it is common to include participants through purposive sampling [17], selecting individuals based on specific purposes associated with addressing the research question or objective of the study [13,17]. Participants who met the inclusion criteria were recruited consecutively from the initial sample of 140 subjects, and data collection ceased when the information obtained in the interviews became repetitive [17]. Of the 140, 54 were asked, 4 did not want to participate and 15 did not answer or could not be interviewed. The final sample size was 35 participants, as no new data were obtained.

The inclusion criteria consisted of: a) adults over 18 years of age, b) with a history of stroke (with a medical diagnosis) more than 6 months ago, regardless of etiology, c) residing at home, d) Functional Ambulation Categories ≥3 (able to ambulate). Exclusion criteria: a) patients with cognitive impairment Mini-Mental Cognitive Test score >24 and/or alterations in verbal communication (no aphasia), b) refusal to participate.

Data collection

Based on the phenomenological design, first-person data collection tools (unstructured and semi-structured interviews) and researcher's field notes were used simultaneously [17]. The first phase of data collection was carried out from September 2021 to April 2022 by means of unstructured interviews. In the second phase carried out from April 2022 to July 2022, a question guide was developed from the data obtained in the first phase

(participants P01 to P03) and through a triangulation process between the research team members (CDA, ABE, PRP) that served as the basis for the format of the semi-structured interviews (participants P04 to P35) (Table 1).

The first interview was conducted face-to-face by CDA and ABE, whereas the remaining interviews ($n = 34$) took place *via* a private video chat room, due to the geographic distribution of the sample. All interviews were conducted and recorded with the written permission of the participants prior to the interview. Each participant received a personalized invitation to a videoconference by the Microsoft Teams platform (*Microsoft Corp., Redmond, WA, USA; version 24256.2502.3123.1, 2023*) as part of the institution's Microsoft 365 Education Subscription and under university security protocols. The interviews were transcribed verbatim, and a total of 1194 min of recordings were obtained. In addition, 35 field notes were collected by the researchers during the interviews [17]. To ensure confidentiality, each participant was assigned an alphanumeric code and the interviews were stored and password-protected by the research team until analysis and then destroyed.

Table 1. Interview procedure.

Unstructured interviews	
What is your experience of physical activity after stroke?	
Semi-structured interview guide	
Issue/Topic	Questions
Physical activity and physical exercise	Before the stroke, what did you consider physical activity and exercise to be like? What about now? What aspects influence whether you allocate more or less days/hours to the activities you can do? Among the activities you do now, which ones give you the most satisfaction? Why? Why and how do you do them? What information have you received about the physical activity you can do to "fight the after-effects of stroke? What activities do you find most strenuous? Which activity is the easiest for you physically and/or mentally?

Prior to the interviews, sociodemographic data, including age, sex, place of residence, and the presence or not of a caregiver; as well as clinical data, including months since stroke, type of stroke, cerebral hemisphere affected, the Barthel Index (BI), and the International Physical Activity Questionnaire short version (IPAQ-SF), were collected in the participating centers through an encrypted data application [18]. The IPAQ-SF provided the minutes performing moderate-to-vigorous physical activity during the week [19], which allowed classifying participants complying with the WHO recommendations for adults living with disability (i.e., 150 min of moderate-to-vigorous PA [3].

Data analysis

The thematic framework method was used for data analysis, according to Giorgi's model [20]. This model presents five stages of data processing (Figure 1).

Subsequently, in both interview phases, a coding grid was created with the units of meaning, their groups, and the identified themes. Within this grid, narratives were identified that justified the results obtained [21]. This was followed by group sessions between the researchers. In these sessions, the themes obtained in both interview phases were analyzed and compared. Subsequently, in the triangulation, the final themes were obtained and decided by consensus among all the researchers involved. Finally, the synthesis of this information was transmitted to 30 participants to check that no relevant information had been forgotten. As a deviation from the published protocol [12], no qualitative software was used to analyze the data. For the analysis, the Excel program was used to organize and share the coding process (Figure 1).

Criteria for rigor and quality

To ensure the methodological quality of the study, the Standards for Reporting Qualitative Research were followed [22] together with the Consolidated Criteria for Reporting Qualitative Research

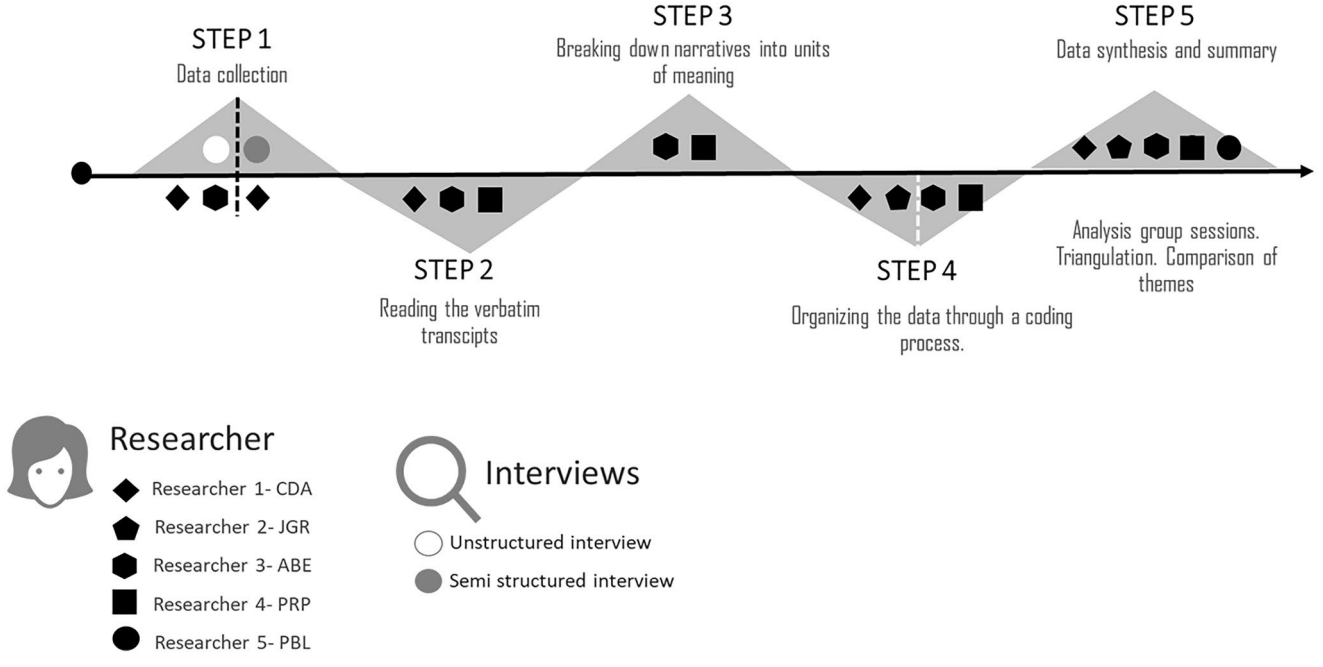


Figure 1. Description of the data analysis process.

Table 2. Trustworthiness criteria.

Criteria	Techniques Performed and Application Procedures
Credibility	Investigator triangulation: Team meetings were organized during the analysis of the situation, to design the questions for the semi-structured interviews, to compare the results and to identify the final results. Some of the participants read the preliminary results and agreed with them.
Transferability	In-depth description of the study, providing data and describing the study design and its different sections (context, research team, reflexivity process, sampling, inclusion criteria, data collection and analysis).
Dependability	Audit by an external investigator, responsible for the evaluation of the study protocol, with special attention to the method and implementation process during the study.
Confirmability	Researcher triangulation, triangulation of data collection. The reflexivity process was carried out by describing the positioning of the researchers; reflexive debriefing by the researchers during data collection and analysis. An interpersonal reflexivity process was carried out during the different stages of the study,

[23] (https://www.equator-network.org/) (Supplemental material). The techniques and application procedures used to check reliability are described in Table 2. Specifically, to achieve dependability, the researcher PBL supervised the implementation of the protocol. Also, the researcher JGR, given his extensive experience in qualitative research, guided the study, advising in the different phases which were the most valid strategies to maintain rigor.

Ethical considerations

This study was approved by the Research Ethics Committee of the Community of Aragón (internal registration number: PI21/333). Furthermore, this study was conducted in accordance with the principles of the Declaration of Helsinki. Permission to record audio and video was obtained from the participants by means of an informed consent form.

Results

A total of 35 participants (12 women, 23 men) with a mean age of 57.2 years come from 24 cities of seven different regions of Spain participated in the study. They showed the experience of a section of people who had had a stroke more than 6 months ago, and who live in their own home, walk independently and have no communication barriers. In particular, the present study explored these adaptations in a profile of stroke survivors able to walk, 40% of whom are independent (BI = 100) and 60% mildly dependent (BI ≥ 60) in activities of daily living. Twelve (34,3%) of the 35 participants needed help from a caregiver. The sociodemographic and clinical characteristics of the participants are shown in Table 3.

Three specific themes emerged from the data analyzed: a) Changes in the experience of physical activity and exercise adaptation; b) Reasons for and against the practice of physical activity and exercise; c) Experiencing tiredness and fatigue. Table 4 shows a summary of the coding tree, with meaning units identified from narratives with relevant information, clusters of common meanings and, finally, the main themes.

Five participants gave their opinion on the synthesis of the results, indicating that their experience of PA was reflected in the information showing the different experiences without forgetting any relevant aspect.

Changes in the experience of physical activity and exercise adaptation

The participants described the characteristics of the activities and exercises they were able to perform, comparing them with their situation prior to the stroke. Pre-stroke activities were defined as sports, since they gave them the nuance of greater perceived effort, energy consumption and duration, together with the pleasure they generated as hobbies that they previously enjoyed. After the stroke, all activity and exercise lost its playful nature, due to the greater difficulty, effort and energy consumption required, becoming instead an obligation or necessity, considering it indispensable due to its benefits.

> Well, now, physical activity is a must and before the stroke it was a good hobby I had. (P33)

> I exercise every day; for me this is my current job. I go to the gym every day, I work out for 3 hours, 2 and a half hours, 3… Whether it's raining, windy, hot, cold… That's my job. (P28)

The perception of post-stroke intensity increased, limiting their ability to reach the same levels of cardiovascular effort, even though they knew that the activities were the same. They even define PA as anything other than sitting, since even getting out of bed or doing household chores is perceived as an effort.

> Maybe when I didn't have the stroke, of course, for me going shopping, carrying bags and climbing the stairs was not a physical activity, but now it is, that's why, that aspect has changed. (P08)

> Now, basically, getting out of bed and going to the bathroom is hard for me because of the effort. And there the effort is… it's unbelievable, but that's just the way it is. (P16)

Activities after stroke were described as "done differently", at a lower intensity, reducing speed and pulse rate due to the difficulty to include and maintain them. Tasks that they would never have thought of as costly, became demanding and energy demanding, and were avoided, adapted, or substituted as the main strategies.

> To get the heart rate up… No, no. I can't do such a vigorous activity to get the… to get the heart rate up like it used to. (P33)

> I used to do a lot of things in one hour and now maybe an hour is not enough time, now you move at a different speed. (P01)

> The other day I went to a notary, I parked the car - I, I measured it, right? - 450 meters from the entrance of the house to the notary's office…. … … a quarter of an hour through Barcelona. This is my speed at the moment. (P18)

Walking was the activity that participants most compared before and after their stroke, due to its applicability and feasibility in their daily lives, describing its characteristics in terms of speed, distances, and effort. Walking is most often performed to get to places by choosing long paths or uphill slopes, or as a way to monitor their evolution by paying attention to the speeds and distances covered.

> Now, besides going out for coffee, I usually go out for a long walk in the morning, of course, I go to more distant places, right? yes, I combine coffee with (laughs) moving around a bit. I go for a walk around the park, right?. (P11)

> I normally walk every day, except if it's very windy or raining; I walk every day for half an hour or three quarters of an hour. If I can't walk for whatever reason, I get on my bicycle (…) at home, which for me is already a big effort. (P01)

The participants narrated that they delegate the burden of exercise to rehabilitation, not wanting to perform other demanding exercises outside of that environment, in order to prioritize

Table 3. Sociodemographic and clinical data of the participants..

Code	Age	Sex	Residence Place	Time since strokE (Months)	Caregiver	BI	WHO Recommendations (150 min of MVPA according to IPAQ-SF)
P01	58	Women	Zaragoza	139	No	70	No
P02	50	Women	A Coruña	114	No	90	Yes
P03	54	Women	Burgos	35	No	75	No
P04	62	Men	Huesca	30	No	100	Yes
P05	59	Women	Zaragoza	43	No	95	No
P06	61	Women	Ferrol	17	No	95	No
P07	50	Women	Ferrol	67	Yes	95	No
P08	50	Men	Canet del mar	24	Yes	100	No
P09	69	Men	Sabadell	148	Yes	100	Yes
P10	73	Men	Zaragoza	100	No	100	No
P11	73	Men	Huesca	42	No	100	No
P12	51	Men	Cornella de Llobregat	36	Yes	95	Yes
P13	72	Men	Valladolid	8	No	100	No
P14	64	Men	Torrelles de Llobregat	49	Yes	85	No
P15	65	Men	Burgos	10	No	85	No
P16	58	Men	Vitoria	30	Yes	80	Yes
P17	71	Men	Sanlúcar de Barrameda	46	No	95	Yes
P18	66	Men	Sant Cugat del Valles	68	No	100	No
P19	59	Men	Alpedrete	44	Yes	95	No
P20	58	Men	Bilbao	7	No	95	Yes
P21	61	Women	Madrid	148	No	100	Yes
P22	45	Women	Galapagar	130	No	100	Yes
P23	58	Men	Barboles	12	No	100	No
P24	24	Men	Barbastro	36	Yes	95	No
P25	62	Men	Zaragoza	65	No	95	No
P26	43	Men	Esplugues de Llobregat	79	No	100	Yes
P27	27	Women	Xove	103	No	100	No
P28	52	Men	La palma del Condado	55	No	95	Yes
P29	79	Women	Burgos	35	Yes	80	Yes
P30	60	Women	Oña	17	Yes	70	Yes
P31	50	Women	Ferrol	35	No	100	Yes
P32	60	Men	Zaragoza	40	No	90	No
P33	46	Men	Zaragoza	44	Yes	85	Yes
P34	43	Men	Marchena	46	No	100	No
P35	70	Men	Huesca	173	Yes	95	No

BI: Barthel Index; IPAQ-SF: International Physical Activity Questionnaire Short-Form; MVPA: equivalent combination of moderate and vigorous intensity PA; PA: physical activity; WHO: World Health Organization.

Table 4. Summary table with themes, groups of common meaning and meaning units.

Meaning units	Groups of common meaning	Theme
Sport vs. obligation and necessity. Perceived intensity.	Comparing pre- and post-stroke activities and exercises.	Changes in the experience of physical activity and exercise adaptation.
Modifying the intensity (speed and heart rate). Adaptations.	Factors that modify the characteristics of the activity or exercise.	
Choosing feasible exercises. Prioritizing rehabilitation. Challenges.	Impact of perceived exertion.	
Satisfaction, affinity, and relevance. Excuses.	Personal goals.	Reasons for and against practicing physical activity and exercise.
Fear of falling or pain. Choosing modifiable exercises.	Decisions according to the type of activity to be performed.	
Accessibility issues. Meteorological factors.	Decisions due to the environment.	
Fatigue vs. tiredness. Overexertion and maladaptations.	Perception of metabolic expenditure.	Experiencing tiredness and fatigue.
Anticipation and preparation. Strategies for recovering energy.	Impact on participation.	

their efforts for rehabilitation. However, some participants try to adapt, set themselves challenges, try new activities and maintain a higher level of exercise after stroke, choosing exercises and activity options that are feasible to do, even if they had not experienced them.

> Now, after the stroke, I am trying, above all, to give priority to rehabilitation. To move, to see if I am getting stronger and that is what I am doing now, fighting, and struggling, yes. (P13)

> What I do is, as a priority, in the mornings I go to the physio and in the afternoons, let's say, I go for a quiet walk. Of course, for me it's a physical activity. (P07)

> Now I can't do what I did before. I would like to go for a bike ride, I can't, but I can do this in the water, and I would never have thought of it… Well, I'm going to do it. Why not?. (P02)

> At the moment, I'm able to swim well underwater with one arm. I don't get very far, but I can do it. (P12)

I'm doing the elliptical, some TRX and abs… And then I'm doing squats on a trampoline I have. To improve my balance, because it's really bad; my balance is very damaged, very much. And well, that's the activity I'm starting to do now… with continuity. (P19)

When we do outings in the countryside, in the mountains, at the beginning I'm a little bit more apprehensive because of the unevenness of the roads… I like it a lot more, because in the city I get bored…. Then it's a matter of looking for something to get out of that routine; it's always good for you. (P15)

Reasons for and against the practice of physical activity and exercise

On a personal level, those who undertook PA described the satisfaction they felt from doing it, especially because of previous affinity, experiencing their progress, or relevance outside the clinical environment that drives them to do it. Regarding functioning, they also expressed the need to release energy and emotional tensions, which was a determining factor for their decision to do it on a continuous basis as an outlet.

Well, it's true that when… I didn't ride my bike for so long, the first time I rode it, I was scared. I remember that I got emotional and all when I was riding it. (P34)

Physical activity is good. For me it's like an outlet, right now I mean. Well, it's like… look, the body needs it a bit and… well, in the end you feel better. Even if you have to sit down and rest, but in the end you really feel better. (P07)

I put in less effort, but at least I am able to ride my bike, which gives me a lot of satisfaction. (P20)

My body needs to vent its energy in some way. So, with exercise, for me, doing sports, going to the gym helps me a lot. (P27)

… seeing this man what had happened to him and all, well, physical activity is of tremendous importance. (P33)

For those who admitted not engaging in PA, they made "excuses" for not leaving their comfortable routine and deciding not to do anything, because it generated insecurity. Moreover, laziness and sluggishness caused by inactivity create a vicious circle.

More than effort, it's the fact of dedicating… The time, that consistency. (P24)

It's a tremendous effort for me to get started. However, once I get started, it's a bit easier, but it's really hard for me to start, I feel really lazy. (P22)

So, in the confinement it has been great and in the confinement, I exercised strictly every day. Now, ugh… Well, when there's not one excuse, there's another. Then the laziness will get the better of you. (P26)

Because they have also told me which exercises, I can do…Then I adapt and do the ones I like the most and the ones I don't (laughs). The ones I like the most are the ones that, mmm… don't cause me pain (laughs)… I don't want to strain, I'm afraid that, by straining too much I'll stiffen up and then I'll be in pain all day long, right? (P11)

The type of activity to be performed was fundamental, since the difficulty in adapting the PE to be able to perform them with only one limb made them very fearful of hurting themselves or falling. For this reason, they usually chose exercises that they could modify with certain solvency and comfort, which would allow them to progress in their practice and development. The participants usually begin with static, controllable activities such as the adapted exercise bike, rather than walking on the treadmill. They do not usually choose to start by swimming, as their ability to float is already too difficult.

You know? But now… Man, I could do it with the right side, but I'm also very scared because I think: "Oh my, if I screw up my right side, what will I do?". (P19)

It's not that I get tired; it scares me a lot and also, hmmm (clicks tongue) I have to be more aware of, of buoyancy. Before it was a more natural thing, now it's… well, I have to be aware not… not that I'm going to drown, because I'm sure I won't drown, because I swim or used to swim quite well, but… it makes me a little nervous. (P19)

For example, running. I run badly….I run like a… a duck, come on. And… I'm very afraid there to trip and fall. Very scared…when I didn't have a stroke, you always put your hands down or something to soften the blow, and I'm afraid of falling. (P19)

The lack of accessibility of the environment was described as a sufficient reason to avoid PA. Regarding accessibility, going out into the street was perceived as a challenge due to the obstacles and slope of the pavement. Other environmental aspects such as meteorological factors that often lead to inactivity, and more specifically, the temperature of the sports facilities, which generate changes in their perception of energy expenditure.

Within the advances available to us, I use the stationary bicycle. (P10)

Going out to the center is very difficult for me, because … when there are a lot of people, I am afraid that someone will push me or something and I will go to the ground. So, I limit myself to this, to being at home and so on. (P13)

Look, my street has a 21% slope: … Just think of that alone, and in order to leave the house and walk to the car - which is parked, I have to climb up stairs. (P18)

The thing is that now it's been a week that I: "I don't go out now". If I go out now, I, I just melt, …… and you go out to the street and (laughs) you come back with third degree burns… I can't bear 35 degrees out there in the sun. (P14)

Swimming, which I liked very much. Now I don't go swimming for one reason, because at the indoor pools the water is not warm enough for what I need, because I have spasticity. So, I come out of the water stiff, like totally stiff, stiff, stiff..... So, I've stopped doing that. (P22)

Walking is easy. I mean, walking, most days, I can do 4 km or more without noticing, so, fine. The bicycle ugh… The bicycle makes me very lazy because in winter it's cold, in summer it's hot. (P26)

Experiencing tiredness and fatigue

Participants were unable to differentiate between tiredness and fatigue, whether physical or mental, as they often referred to the subjective effort involved in exercising. They described the factors related to the perception of fatigue, as well as the fatigue caused by the performance of light daily activities that leave them depleted of energy, and the influence that both situations have on resuming participation in the form of overexertion.

Let's see, I don't do any intense activity because I can't. Not my head or anything physical, I can't do it. All the activities I do are moderate. (P07)

I feel tired with anything… Well, yes, cleaning the windows, the kitchen. I mean, what I notice is that I get tired, I get fatigued… so mmm doing anything makes me tired. (P05)

In addition, they recounted the anticipation and preparation for exercise and the impact of exercising. Moreover, muscle fatigue

generated maladaptations in the performance of the activity, which gave them an additional reason to stop. Also, they were particularly fatigued on the less affected side of the body, which had to make a greater effort to compensate for the movement of the more affected hemibody.

> I want to start running and, and I have told… these guys that, that they should prepare an intensive program for me. (P19)

> Quite a lot of effort, because of course, I have half of my body which has to move the whole body. (P25)

> They are additional fatigues, I mean, when I'm walking a lot… if I have to stop sometimes it's because my shoulder hurts a lot, because I'm pulling my shoulder a lot. (P15)

They also shared the strategies employed to regain energy, such as taking breaks. Sleep is a vital choice that they value in their daily lives, as well as knowing their limits and the effects of breaching them.

> To do more I personally just need to do a little bit and I can rest, a little bit more and rest. In other words, something that allows you to do it and rest. (P07)

Discussion

A sample of 35 stroke survivors living at home in several locations in Spain described their experiences concerning PA and PE, most of the time by comparing activities they remembered practicing before the stroke with their current activities. This aligns with previous studies [4] showing the difficulty in returning to active participation [24] against those who often resume the types of PA they did before the stroke [25]. Similarly to studies carried out in other countries [5, 8,9,26], our findings also reflected a change in the perception of PA and PE after the stroke, transforming it from being an idle activity carried out in leisure time to an obligation. This change may be key in understanding the development of sedentary behaviors and the non-acquisition of active routines [27], highlighting that self-efficacy and the previous experience can improve adherence to PA and PE [28].

The participants shared their proposals for adapting the performance of PA and PE to their current capacity, as noted in a study by Fallahpour et al. [29]. All these adaptations seemed to influence the perceived effort, in line with previous authors [30]. However, our findings delve deeper into the strategies adopted by participants to cope with this increase in their perceived exertion, describing how they avoid, modify or substitute activities. These findings will help to promote preferences adjusted to PA intensity tolerance of stroke survivors [31]. Notably, the present study provided valuable information about stroke survivors with good functional status, able to walk, preserved cognitive capacities, and no levels of moderate or severe dependence in their daily lives.

Among the PA and PE proposals made by the participants after the stroke, walking stands out as the activity they are best able to perform, which is useful and necessary for carrying out social activities. According to Lord & Wesselhoff [32], 70% of stroke survivors regain ambulation, but only 37-60% of stroke survivors achieve mobility in the community even four years post-stroke [24]. Our participants, walking independent, presented an average of more than four years of evolution since the stroke. Despite these PA facilitating factors, most of the participants failed to comply with the WHO recommendations of PA [2,33]. Therefore, it is essential to understand other limiting factors of PA influencing their sedentary behavior. These included factors such as architectural barriers in the city and meteorological and environmental factors such as rain or temperature [24], which was reflected in the narratives of the participants from 24 cities in different regions of Spain with widely diverse climates. Therefore, despite ambulation is the most useful and effective activity for the performance of community activities. Our participants, able to walk, showed limited community transfer or performance of daily activities. In fact, only 15 (43%) of the 35 participants met the WHO weekly PA recommendations. This situation could show the lack of awareness of perceived exertion in everyday activities and the need for health education [34,35].

The participants described that they prioritize and reserve their efforts for their rehabilitation sessions. They also reported a desire to face new challenges. In light of our findings, it seems necessary to continue promoting a paradigm shift in which individualized guidelines are promoted for PA to be performed outside the health care setting, in a normalized environment [36–38].

Our findings highlighted the multifactorial nature of decision-making regarding PA and PE in stroke survivors, describing the ambivalence of personal aspects in incorporating PE in their lives. As noted by previous authors [5,39], the promotion PA after a stroke requires assessing the synergies between motivation and capacity and integrating these synergies into interventions. Participants in our study identified factors that they considered to be related to performance of PA and PE (person, environment and behavior), consistent with previous findings [40].

The participants reported the need for physical and mental preparation prior to the performance of PA and PE, which was also reflected by other authors previously as a self-regulation strategy, by anticipating and overcoming barriers [40]. Our results showed that maladaptations, in some cases, occurred when the strategies failed. Furthermore, the participants indicated the factors influencing the selected activity, showing that few people were able to make this leap to the incorporation of moderate or intense PA in a normalized social environment once the initial rehabilitation phase was completed.

The participants described the ways in which they have adapted the performance of PA, demonstrating a process of resilience and problem solving, which is considered a personal capacity for adaptation beyond the after-effects of the stroke [40]. To date, most research has focused on developing intervention plans to increase the level of PA but neglecting aspects such as self-efficacy and self-concept, or expectations of results [4,5]. Therefore, a change is needed in the rehabilitation model to consider the multifactorial relationships that condition adherence to PA and PE and the various adaptation options, considering the individual's perception.

Our findings showed the different experiences of physical and mental tiredness and fatigue based on the perception of energy expenditure. Almost 50% of people who have suffered a stroke experience post-stroke fatigue regardless of the degree of recovery. Our results show the need for daytime and nighttime rest times and awareness of limits as coping strategies in those with an adequate level of PA to tolerate perceived exertion and balance exercise levels, in line with previous studies [41]. It also reveals the lack of health education, awareness, or accessibility of useful tools for self-perceived effort or records of activity that can help people to plan the amount and/or intensity of PA to be performed per week, as well as possibilities to graduate it, adapt it and combine it with rest times.

Need for further research

Future studies should analyze the experience of physical activity and physical exercise in this high functional capacity group of stroke survivors during the first 6 months post-stroke. In addition

to observing the segment of more dependent stroke survivors, both during the first 6 months and thereafter.

Strengths and limitations

Regarding the strengths of this study, this is the first qualitative research carried out in Spain in which information was collected on the experience of these people residing in their own home and their natural environment regarding the performance of PA and PE, with little updated qualitative [42] and quantitative research [25] in other countries. In contrast, the limitation of this study is related to that these results cannot be extrapolated to all stroke survivors, due to the nature of the research question, the qualitative design selected and sample characteristics (i.e., cover only people with walking without aphasia or cognitive impairment).

In conclusion, the results show the individual perspective on readaptation to PA and PE after stroke without severe sequelae in Spain, considering the sequelae that limit activity, together with the preferences of individuals and the previous history of active lifestyle, along with the multiple influences of the environment on this behavior when the stroke sequelae do not limit ambulation and therefore the possibility of movement.

Acknowledgments

The authors thank all the participants and families who have made this study possible. We thank all the collaborating centres involved in the recruitment of study participants: ADACECO (Asociación de Daño Cerebral de A Coruña) in A Coruña; AENO (Asociación de Enfermos Neurológicos Oscense) in Huesca; AIDA (Asociación de Ictus de Aragón) in Zaragoza; ASPAYM (Asociación de personas con lesión medular y otras discapacidades físicas) in Burgos; Centro de neurorrehabilitación (Clínica de Rehabilitación Neurológica Sant Cugat) in San Cugat del Valles; CIRON (Centro Integral de Rehabilitación ON) in Valladolid; freelance physiotherapists in Madrid (Lezcano Fisioterapia) and Sanlúcar de Barrameda; INEURO (Neurorrehabilitación y Atención al Neurodesarrollo) in Sevilla; NEUFIS (Centro de Fisioterapia y Neurorrehabilitación) in Vitoria; NEURAXIS (Rehabilitación Neurológica y Desarrollo Infantil) in Ferrol; NEUROESPLUGUES (Centre de Rehabilitació Neurològica) in Esplugues de Llobregat; Rehabilitación El Carmen in Zaragoza.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This study was supported to translation by a research award grant from the Colegio Profesional de Terapeutas Ocupacionales del Principado de Asturias (COPTOPA) and no financial benefits are derived to the authors from this study. Cristina de Diego-Alonso, Patricia Roldán-Pérez, Almudena Buesa-Estéllez and Pablo Bellosta-López are members of the research group MOTUS supported by "Gobierno de Aragón" (n. B60_23D). The funders did not have any role in this study.

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Supplementary material

Changes in the experience of physical activity and exercise adaptation.
Comparing pre- and post-stroke activities and exercises.
Sport vs. Obligation and necessity.
"Well, right now it's an effort and a chore... A tough chore... it's hard work. Before it was fun; before I used to do sports and I had a good time, but now... I just… try to do a good job." (P16) *"Well, now, physical activity is a must and before the stroke it was a good hobby I had."*(P33) *"I exercise every day; for me this is my current job. I go to the gym every day, I work out for 3 hours, 2 and a half hours, 3... Whether it's raining, windy, hot, cold... That's my job."*(P28) *"Before I was very lazy - before the stroke - ..... but now, well, I see it as - I'm not going to say as a necessity, because I also like to do it - but of course, I also see it as an obligation, I see that I have come a long way, ... and I don't want to stay... - to stay quiet and comfortable - I don't want to go backwards in my sensations, rather, I want to continue advancing as much as possible…"* (P15)
Perceived intensity.
*"Going shopping, up until I get home, is an enormous effort for me. On top of that, I have to wait half an hour at the fishmongers. Of course, that's a lot of effort." (*P01). *"At the beginning, when, especially given my physical condition, I did, that… walking uphill... I noticed a much greater effort, right? Mainly in those situations. Of course, I was a bit... well, a bit fat and of course, well, I had to make the effort... But on the inside, I didn't feel tired."* (P10) *"Maybe when I didn't have the stroke, of course, for me going shopping, carrying bags and climbing the stairs was not a physical activity, but now it is, that's why, that aspect has changed."* (P08) *"Now, basically, getting out of bed and going to the bathroom is hard for me because of the effort. And there the effort is... it's unbelievable, but that's just the way it is."* (P16)
Factors that modify the characteristics of the activity or exercise.
Modifying the intensity (speed and heart rate).
"To get the heart rate up... No, no. I can't do such a vigorous activity to get the... to get the heart rate up like it used to." (P33) *"You know I really like going to Zarautz for hiking. So, I have taken the opportunity to do it every day. I used to get up and go hiking. Not as much as I did before, going more slowly. But well, I've been able to walk all the way to a valley."* (P04) *"I used to do a lot of things in one hour and now maybe an hour is not enough time, now you move at a different speed."* (P01) *"The other day I went to a notary, I parked the car - I, I measured it, right? - 450 meters from the entrance of the house to the notary's office. To walk 450 meters: ... ... a quarter of an hour through Barcelona. This is my speed at the moment."* (P18)
Adaptations.
"Practicing boxing with one hand, hiking at a slower pace. All kinds of things, even if it's just going down steps with a lower step, I consider it physical activity as well." (P24) *"Truly, so to speak, the strongest efforts, ... I decline. There is nothing that I ... invest a lot of strength in. Besides, I try to avoid any kind of exaggerated exertion like that."* (P08)

Impact of perceived exertion.
Choosing feasible exercises.
"Now, besides going out for coffee, I usually go out for a long walk in the morning, of course, I go to more distant places, right? yes, I combine coffee with (laughs) moving around a bit. I go for a walk around the park, right?." (P11) *"And then going for a walk, I'm not a big trotter either, but, but now I try, for example, when I have to go shopping for anything or leave the house, I don't go in a straight line, I follow a longer route you know? To walk more."* (P08) *"I normally walk every day, except if it's very windy or raining; I walk every day for half an hour or three quarters of an hour. If I can't walk for whatever reason, I get on my bicycle (...) at home, which for me is already a big effort."* (P01) *"No swimming. And walking, I walk little by little... almost every day. I go out... for an hour or so."* (P05) *"Well, lately I didn't do group sports anymore, because they were individual, but I did go walking a lot... I went to the swimming pool, quite a lot, right? And since I have a bad back, I have given up everything that involving a racquet. And now nothing, now doing sports means going for a walk; nothing, going to get the newspaper, (laughs) going for a coffee, right? And just going to rehab. No, no gym or anything, I mean... Well, and at home doing a little bit of, of stretching."* (P11)
Prioritizing rehabilitation.
"Now, after the stroke, I am trying, above all, to give priority to rehabilitation. To move, to see if I am getting stronger and that is what I am doing now, fighting, and struggling, yes." (P13) *"What I do is, as a priority, in the mornings I go to the physio and in the afternoons, let's say, I go for a quiet walk. Of course, for me it's a physical activity."* (P07) *"Before, I never used the exercise bike. A physio comes... ...and the last fifteen minutes I ride the bike, and he sets the pace. "Faster now, faster, ... more, more, more, more, more, more, more, more". And at the end I look like a, a Perico Delgado or, or, or, or Induráin, you name it...."* (P14) *"In, in AENO I'm a... In the beginning I was doing three hours a week. Now with the pandemic, with all this I've, I've reduced it. And with the other trainer, it's half an hour, but it's very intense. And besides, every day - if I don't go to rehab - I do my exercises at home."* (P11)
Challenges.
"Now I can't do what I did before. I would like to go for a bike ride, I can't, but I can do this in the water, and I would never have thought of it... Well, I'm going to do it. Why not?." (P02) *"At the moment, I'm able to swim well underwater with one arm. I don't get very far, but I can do it."* (P12) *"Well, normally I always try to achieve my maximum in physical activity, you know? I mean, I try to push myself a little bit more every day and things like that. But little by little. I accept that this is the way things are, you know."* (P12) *"I'm doing the elliptical, some TRX and abs... And then I'm doing squats on a trampoline I have. To improve my balance, because it's really bad; my balance is very damaged, very much. And well, that's the activity I'm starting to do now... with continuity."* (P19) *"When we do outings in the countryside, in the mountains, at the beginning I'm a little bit more apprehensive because of the unevenness of the roads… I like it a lot more, because in the city I get bored.... Then it's a matter of looking for something to get out of that routine; it's always good for you."* (P15)

Reasons for and against practicing physical activity and exercise.
Personal goals.
Satisfaction, affinity, and relevance.
"Well, it's true that when... I didn't ride my bike for so long, the first time I rode it, I was scared. I remember that I got emotional and all when I was riding it." (P34) *"Physical activity is good. For me it's like an outlet, right now I mean. Well, it's like... look, the body needs it a bit and... well, in the end you feel better. Even if you have to sit down and rest, but in the end you really feel better."* (P07) *"I put in less effort, but at least I am able to ride my bike, which gives me a lot of satisfaction."* (P20) *"My body needs to vent its energy in some way. So, with exercise, for me, doing sports, going to the gym helps me a lot."* (P27) *"... seeing this man what had happened to him and all, well, physical activity is of tremendous importance."* (P33)
Excuses.
"Well, I can't say. I can't say, because as far as physical activity is concerned, I'm quite limited. Even now we've been on vacation with AENO, and you realize that when you get out of your routine, you feel insecure." (P35) *"More than effort, it's the fact of dedicating... The time, that consistency."* (P24) *"It's a tremendous effort for me to get started. However, once I get started, it's a bit easier, but it's really hard for me to start, I feel really lazy."*(P22) *"So, in the confinement it has been great and in the confinement, I exercised strictly every day. Now, ugh... Well, when there's not one excuse, there's another. Then the laziness will get the better of you."*(P26) *"Because they have also told me which exercises, I can do…Then I adapt and do the ones I like the most and the ones I don't (laughs). The ones I like the most are the ones that, mmm... don't cause me pain (laughs)…I don't want to strain, I'm afraid that, by straining too much I'll stiffen up and then I'll be in pain all day long, right?."* (P11)
Decisions according to the type of activity to be performed.
Fear of falling or pain.
You know? But now... Man, I could do it with the right side, but I'm also very scared because I think: "Oh my, if I screw up my right side, what will I do?." (P19) *"The only activity is, from time to time, to go for a walk for a while. And if my groin gets tired and I feel pain, then I've really screwed up, right? I try not to have pain. You know, no pain."* (P11) *"It's not that I get tired; it scares me a lot and also, hmmm (clicks tongue) I have to be more aware of, of buoyancy. Before it was a more natural thing, now it's... well, I have to be aware not... not that I'm going to drown, because I'm sure I won't drown, because I swim or used to swim quite well, but... it makes me a little nervous."* (P19) *"For example, running. I run badly….I run like a... a duck, come on. And... I'm very afraid there to trip and fall. Very scared…when I didn't have a stroke, you always put your hands down or something to soften the blow, and I'm afraid of falling."* (P19)
Choosing modifiable exercises.
"Within the advances available to us, I use the stationary bicycle." (P10) *"Now I have to try the bicycle, let's see how it goes. The thing is that the bicycle is very complicated, because I have to do it with only one hand. And I don't dare, because I want to hook my right hand to the handlebars, but no, I don't dare. I don't dare because I know I have to do it... it's going to be very hard, I'm going to laugh a lot, but well...".* (P12)

Decisions due to the environment.
Accessibility issues.
"Going out to the center is very difficult for me, because ... when there are a lot of people, I am afraid that someone will push me or something and I will go to the ground. So, I limit myself to this, to being at home and so on." (P13) *"Walking through the streets here in Torrillas. That... this, this looks like a minefield. (...) but come on, living here in Torrillas is, I don't know, 300 meters from home. No, no, no more. But well, for, for me it's like doing a marathon, you know?"* (P14) *"Look, my street has a 21% slope: ... Just think of that alone, and in order to leave the house and walk to the car - which is parked, I have to climb up stairs."* (P18)
Meteorological factors.
"The thing is that now it's been a week that I: "I don't go out now". If I go out now, I, I just melt, ... and you go out to the street and (laughs) you come back with third degree burns… I can't bear 35 degrees out there in the sun." (P14) *"Swimming, which I liked very much. Now I don't go swimming for one reason, because at the indoor pools the water is not warm enough for what I need, because I have spasticity. So, I come out of the water stiff, like totally stiff, stiff, stiff. And I have a very hard time and it's very difficult for me to walk. In fact, it's very hard for me to get out of the water because my muscles get so stiff that it's hard for me to get out. So, I've stopped doing that."* (P22) *"Walking is easy. I mean, walking, most days, I can do 4 km or more without noticing, so, fine. The bicycle ugh... The bicycle makes me very lazy because in winter it's cold, in summer it's hot."* (P26)
Experiencing tiredness and fatigue.
Perception of metabolic expenditure.
Fatigue vs. tiredness.
"Trying to maintain my balance, but with the weights; which is, it's double the effort because my balance - as my right leg is affected - it's double the effort of concentration. In fact, the mental fatigue of being concentrated and not losing concentration, because you can fall, tires me more than the physical fatigue." (P18) *"Let's see, I don't do any intense activity because I can't. Not my head or anything physical, I can't do it. All the activities I do are moderate."* (P07) *"I feel tired with anything... Well, yes, cleaning the windows, the kitchen. I mean, what I notice is that I get tired, I get fatigued... so mmm doing anything makes me tired."* (P05) *"Before, many mornings I would go running for a while. 10 kilometers. Now I do 100 meters and whew, I'm really exhausted."* (P16) *"I feel tired with anything... I mean, what I notice is that I get tired, I get fatigued... so mmm doing anything makes me tired. It seems like I'm doing an exercise... who knows..."* (P05) *"I do experience fatigue, but in my shoulder - basically - yes, there comes a... there comes a time, maybe there are days when you overdo it and you get home a mess, but well, it's not the norm - I mean -. You know your limits..."* (P15)
Overexertion and maladaptations.
"Quite a lot of effort, because of course, I have half of my body which has to move the whole body."(P25) *"They are additional fatigues, I mean, when I'm walking a lot... if I have to stop sometimes it's because my shoulder hurts a lot, because I'm pulling my shoulder a lot."* (P15) *"I've, it takes me quite a bit of effort because I have to, I mean, well, I have to strain my shoulder a lot and, and my hip gets pretty achy."* (P15)

Impact on participation.
Anticipation and preparation.
"I want to start running and, and I have told... these guys that, that they should prepare an intensive program for me." (P19) *"well gosh, you almost have to train or prepare or.... you know? It's something that's not operative, really. But I have done it, but that, that's one of the things that I miss a lot in, in recovery and physical therapy centers."* (P19)
Strategies for recovering energy.
"*Now I get tired a lot, but I lie in bed and recover."* (P01) *"To do more I personally just need to do a little bit and I can rest, a little bit more and rest. In other words, something that allows you to do it and rest."* (P07) *"It requires me to make an effort. Yes. When I get out of the, when I get out of the gym it takes me a while to get home. It's not very far because it's - it used to be five minutes from my house - now it takes me a quarter of an hour to get there. It's just that I come out, I come out of the gym tired and well, well, it requires me to sit down for a while from time to time, but nothing else."* (P13) *"Actually, the toughest things, so to speak ... I refuse to do. There is nothing in which I ... invest a lot of strength. Besides, I try to avoid any kind of exaggerated exertion like that."* (P08)

5.6. Estudio cualitativo sobre la participación: artículo 6

Artículo 6: Taking part. Experiences surrounding the return to participation in stroke survivors. A qualitative study.

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Enviado a la revista XXX
(Editorial: XX).
Q3, JIF:XX

CAPÍTULO 6. RESUMEN DE RESULTADOS

Se aporta un resumen de los resultados más relevantes de los artículos que componen la presente Tesis Doctoral (*Tabla 11*).

Artículo	Principales resultados
Artículo 1. *The relationship between levels of physical activity and participation in everyday life in stroke survivors: a systematic review and meta-analysis.*	De los 4.962 estudios identificados, 49 se incluyeron en la revisión sistemática. Los estudios se calificaron como de calidad alta (55%) o regular (45%). En los 23 estudios prospectivos se encontró una amplia gama de metodologías de seguimiento para evaluar la AF y la participación. Se incluyeron siete estudios en el metaanálisis, que mostraron una correlación positiva moderada entre el tiempo de AF y la participación en las actividades de la vida diaria (n=148; r=0,52; P<0,01; I2=81%) en participantes <6 meses después de un ictus, y entre el tiempo de AF y la participación en todas las áreas (n=126; r=0,44; P<0,01; I2=0%) en participantes ≥6 meses después de un ictus. En general, mientras que la AF mostró mejoras significativas con el tiempo, la participación sólo mostró una tendencia.
Artículo 2. *Validity and stability of the International Physical Activity Questionnaire for stroke survivors with preserved walking ability.*	IPAQ-SF mostró una buena validez aparente y de contenido. Se encontraron correlaciones "moderadas" a "fuertes" con la Fitbit Inspire 2 (rho: 0,40 a 0,63), mientras que se encontraron correlaciones "débiles" a "moderadas" con el 6MTW (rho: 0,35 a 0,50). La estabilidad test-retest fue de "moderada" a "excelente" (κ: 0,844 a 0,881; ICC: 0,533 a 0,917).

Artículo 3. *Psychometric Properties of the Spanish Version of the Satisfaction With Daily Occupations and Occupational Balance in Spanish Stroke Survivors.*	La consistencia interna fue aceptable; Cronbach's a 5 .80, 95% intervalo de confianza (IC) [0.75, 0.85]. Se encontró una correlación moderada entre el nivel de participación sumado del SDO-OB y la suma de la satisfacción con la participación (r 5,53). Ambas puntuaciones sumadas SDO-OB se correlacionaron con las puntuaciones del ACS (0,25 < r < .61). Sin embargo, sólo las puntuaciones de la sumada de la satisfacción con la participación se correlacionaron con el componente emocional del EQ-5D-5L (r 5,32). El SDO-OB discriminó entre grupos con y sin cuidador (p 5,001) y no tuvo efectos suelo y techo (<7%). Se obtuvieron buenos coeficientes de correlación intraclase (CCI) para la suma del nivel de participación (CCI 5,91;95% CI [.85, .94]) y la suma de la satisfacción con la participación (ICC 5 .86; 95% CI [.78, .92]). El error estándar de medición y el cambio mínimo detectable fueron de 0,7 y 1,9 puntos, respectivamente, para la suma del nivel de participación y de 4,5 y 12,5 puntos, respectivamente, para la suma de la satisfacción con la participación.
Artículo 4. *Correlations between physical activity levels and participation in high-functioning stroke survivors.*	La ACS mostró correlaciones moderadas con las Kcal/día y el promedio de pasos/día (rho≥0,581) y la AF autoinformada (rho=0,324). La participación en SDO-OB mostró fuertes correlaciones con las Kcal/día y la media de pasos/día (rho≥0,647) y una correlación moderada con la AF autoinformada (rho=0,303). Este estudio encontró una fuerte correlación entre la media de pasos/día y las Kcal/día (rho=0,933), y correlaciones moderadas entre las actividades mantenidas en ACS y la participación en SDO-OB (rho=0,542) y la satisfacción con la actividad (rho=0,448).

Artículo 5. *"More than effort, it's dedicating time and perseverance." Experiences of physical activity and physical exercise in stroke survivor with high functional capacity: A qualitative study.*	Surgieron tres temas: a) Cambios en la experiencia de la AF y la adaptación al ejercicio: Comparación de actividades y ejercicios previos y posteriores al ictus, factores que modifican las características de la actividad o el ejercicio, Impacto del esfuerzo percibido; b) Razones a favor y en contra de la práctica de AF y ejercicio: Objetivos personales, decisiones en función del tipo de actividad a realizar y decisiones debidas al entorno; c) Experimentar cansancio y fatiga: Percepción del gasto metabólico, impacto en la participación.
Artículo 6. *Taking part. Experiences surrounding the return to participation in stroke survivors. A qualitative study.*	Se obtuvieron tres temas: a) Yo, mí mismo y yo: influencia negativa de las secuelas, persistencia en la recuperación de la independencia y lecciones de vida; b) Vida cotidiana: hogar y ocio, trabajo y estudio; y c) Explorando las relaciones interpersonales: relaciones de pareja, en la sociedad y en el entorno sanitario.

Tabla 11. *Resumen de los principales resultados de los artículos que componen la presente Tesis doctoral. AF: actividad física. 6MTW: 6-Metre Timed Walk; ACS:Activity Card Sort; AF: actividad física; IPAQ-SF: International Physical Activity Questionnaire- Short Form; Kcal: Kilocalorías; METs: Metabolic Equivalents of Task; SDO-OB: Satisfaction with Daily Occupations-Occupational Balance.*

CAPÍTULO 7. DISCUSIÓN GENERAL

7.1. Discusión general

La presente Tesis Doctoral ha incorporado el protocolo de investigación de la revisión sistemática con metaanálisis sobre la relación entre los niveles de AF y participación en supervivientes de un ictus y el protocolo del proyecto de investigación multicéntrico Part&Sed-Stroke, parte del cual incluye el diseño metodológico de los artículos 2, 3, 4, 5 y 6. Ambos artículos no aportan datos, sino el diseño metodológico en los que se han basado las investigaciones que forman parte de esta tesis doctoral, permitiendo que dichos protocolos puedan ser replicados en futuros estudios (*Anexo 4*).

La investigación recopiló de forma exhaustiva la información disponible hasta la fecha sobre las relaciones entre los niveles de AF y participación en supervivientes de un ictus confirmando la existencia de esta relación y evidenciando una alta heterogeneidad entre las herramientas de valoración utilizadas para registrar estas variables. En base a lo cual la presente tesis ha propuesto que tanto IPAQ-SF como SDO-OB puedan ser herramientas de referencia para la valoración de estas variables dado que han demostrado adecuadas propiedades psicométricas cuando son administradas en supervivientes de un ictus. Por otro lado, esta tesis doctoral ha demostrado que existe una correlación entre la AF y la participación en supervivientes de un ictus independiente en la marcha y sin alteraciones en las funciones cognitivas y de comunicación. Pero su estilo de vida se ha visto influido tras el ictus, siendo relevante la influencia de diversos factores en la realización de AF y ejercicio físico y el retorno a la participación desde la experiencia de los propios supervivientes de un ictus.

A continuación, se expone una discusión general abordando los aspectos más relevantes que se encuentran expuestos con mayor detalle en cada uno de los artículos que componen el compendio de la presente Tesis Doctoral.

Tras el análisis realizado sobre la literatura científica en relación con la AF y participación en supervivientes de un ictus se reveló la existencia de correlaciones positivas moderadas entre los niveles de AF y participación en supervivientes de un ictus, tanto a los 6 meses del ictus como posteriormente. En concreto, los resultados de los estudios prospectivos que cumplieron criterios mostraron que los niveles de AF parecían

aumentar en las primeras semanas o meses en comparación con los niveles de participación que necesitaron más tiempo. La revisión sistemática con metaanálisis realizada confirma que, el retorno a la participación en la vida diaria después de un ictus requiere de más de 6 meses. Conclusiones que previamente habían indicado otras investigaciones, afirmando que puede llegar a necesitarse hasta 4 años en recuperar la participación previa al ictus en las actividades de la vida diaria [1], y 6 años en volver a la participación en la comunidad [2,3]. Asimismo, nuestros hallazgos contribuyen a desterrar la antigua creencia que afirmaba que no es posible ningún cambio significativo pasados los primeros 6 meses posteriores al ictus [4-7]. Desde este punto de vista, es evidente continuar investigando sobre los cambios que se producen en la reorganización del sistema nervioso central [8] después de 6 meses de un ictus y su transferencia tanto al retorno de la participación [9] como al estilo de vida activo, además de la evolución de este proceso en el tiempo y en relación al envejecimiento natural [10,11]. Por lo tanto, es necesario realizar un seguimiento de los supervivientes de un ictus durante un periodo de tiempo que supere los primeros 6 meses para identificar mejoras significativas en la participación a largo plazo, en línea con estudios previos [1-3].

Por otro lado, se reveló un alto grado de heterogeneidad en las herramientas utilizadas en las investigaciones que abordaron la relación entre actividad física y participación. En este sentido, la mayoría de los estudios incluidos en esta investigación de revisión sistemática, se adhirieron a las recomendaciones de un reciente consenso de expertos sobre variables y herramientas de AF [12]. En cambio, las herramientas utilizadas para registrar la participación no proporcionaron información exhaustiva [13,14], siendo necesario establecer un consenso sobre las variables de participación [15]. Concretamente, tanto BI como SIS, dos de las herramientas más utilizadas en los estudios seleccionados, presentan grandes carencias. En este sentido, BI sólo aborda el nivel de participación en la realización de las actividades de la vida diaria, aportando el nivel de dependencia. Además, a pesar de que SIS es una herramienta que fue diseñada para registrar la calidad de vida tras un ictus [16,17], es la herramienta más utilizada para medir la participación [14]. SIS no cubre de manera uniforme los 9 dominios de actividad y participación de la CIF [18] y no incluyen otros aspectos del constructo de participación como la experiencia subjetiva significativa de la participación o la autonomía percibida [19,20]. Por lo tanto, la información proporcionada en la revisión realizada sobre la correlación entre la AF y la participación (medida principalmente a través de las herramientas de valoración BI y SIS) puede ser incompleta.

Las lagunas detectadas en esta investigación en relación con el conocimiento sobre las propiedades psicométricas de las herramientas de valoración de la AF y participación motivaron los estudios de validación del cuestionario IPAQ y la herramienta de valoración SDO-OB. En relación con el IPAQ, un recientemente consenso de expertos sugirió el uso de este cuestionario para recoger información sobre el tiempo de AF en supervivientes de un ictus [12]. No obstante, un estudio previo destacó la necesidad de investigar las propiedades psicométricas del mismo [21]. En este sentido, los hallazgos de nuestro estudio proporcionaron información pertinente sobre las propiedades psicométrica del IPAQ-SF [22] cuando es administrada a personas españolas supervivientes de un ictus con alto nivel funcional una vez transcurridos los primeros 6 meses. Los hallazgos de nuestro estudio contribuyeron a reforzar el uso de la herramienta de evaluación IPAQ recomendada [23] para el registro de los parámetros de AF [24].

Asimismo, Ruescas-Nicolau et al. (2021) [21] demostraron la validez de *IPAQ- Long Form* en supervivientes de un ictus con altos niveles de AF. A pesar de mostrar un exceso de combinación de AF moderada-vigorosa (AFMV) y un déficit total de AF en comparación con el acelerómetro ActiGraph GT3X+, con el cual mostró una correlación de "moderada" a "fuerte" [21]. En este sentido, *IPAQ- Long Form* sobrestimó el tiempo dedicado a la AFMV y subestimó el tiempo dedicado a conductas sedentarias en comparación con el acelerómetro [21]. En base a los resultados de nuestra investigación, el IPAQ-SF se consideró una herramienta útil para el cribado tanto de supervivientes de un ictus, muy activos como inactivos, después de 6 meses de su ictus con alta capacidad funcional, siendo estos adecuados candidatos para realizar intervenciones específicas para promover hábitos saludables. De forma similar a los hallazgos sobre IPAQ- *Long Form* [21], el IPAQ-SF se correlacionó "moderadamente" con la AFMV registrada con un dispositivo objetivo. Además, demostró una correlación "fuerte" con el total de minutos a la semana de METs. Estos resultados sugieren que, en ausencia de dispositivos de medición objetivos en el contexto clínico, es posible obtener datos correlacionados adecuados con parámetros objetivos administrando tanto IPAQ- *Long Form* como el IPAQ-SF en supervivientes de un ictus. En este sentido, los hallazgos de la presente investigación mostraron una correlación "moderada" entre la AF autopercibida medida con el IPAQ-SF y la velocidad de la marcha medida con el 6MTW. Por lo tanto, nuestro estudio reveló que los individuos con niveles más altos de AF, tienden a mostrar una mayor velocidad al andar. Concretamente, esta información resalta la relevancia clínica de influir en la velocidad de la marcha, dada su asociación con el comportamiento

sedentario en supervivientes de un ictus, como apuntaron autores previos [25,26]. Sin embargo, el hecho de que la correlación fuera "moderada" también respalda que podrían estar influyendo otros factores en el nivel de AF , entre los que se contemplan las secuelas del ictus, los años de evolución, el entorno y el apoyo social [27-29]. Por lo tanto, es fundamental realizar futuros estudios que analicen estas relaciones multifactoriales [30,31].

Además, es necesario tener en cuenta que, las investigaciones previas sobre la estabilidad de los resultados del test-retest del IPAQ-SF en otras poblaciones, con y sin enfermedad, mostraron resultados similares a los del estudio aquí presentados [32].En este sentido, los hallazgos de nuestro estudio de validación del IPAQ-SF reafirmaron la adecuada estabilidad test-retest del IPAQ-SF, respecto a lo cual es necesario destacar que se aplicó un diseño metodológico en el que se incluyó un procedimiento de formación y seguimiento para mitigar el sesgo de evaluación.

En este sentido, el IPAQ-SF se consideró una herramienta clínicamente útil y óptima para los supervivientes de un ictus [33], siendo la única hasta la fecha que permite proporcionar información para evaluar si se alcanzan las recomendaciones de la OMS, en relación con la realización de AF. Es un cuestionario de bajo coste, eficiente en el tiempo y fiable para detectar la inactividad física en los supervivientes de un ictus, recogiendo la actividad realizada en bloques de 10 minutos o más y pudiendo agregar sus resultados para compararlos con las recomendaciones de la OMS.

Finalmente, los hallazgos de nuestra investigación recalcaron la importancia de considerar que las secuelas del ictus, como la fatiga [34] y la percepción del nivel de AF realizado, pueden influir en los tipos y adaptaciones en la AF realizada [35], así como en su percepción de la intensidad y duración de la AF [36]. Por lo tanto, todos estos aspectos deben ser contemplados, con el objetivo de mitigar el sesgo retrospectivo en la administración de esta herramienta [37], pudiendo ser útil el uso del material suplementario para la administración del IPAQ-SF que se elaboró para proporcionar aclaraciones y apoyo a los supervivientes de un ictus para obtener resultados fiables.

En relación a la versión española del SDO-OB [38], los hallazgos de la investigación realizada sobre sus propiedades psicométricas demostraron una buena fiabilidad intraobservador, lo que evidencia la estabilidad de las respuestas aportadas por el SDO-OB cuando estas son recogidas por el mismo evaluador. Asimismo, se encontró una consistencia interna aceptable, similar a los resultados del estudio de Vidaña-Moya et al. (2020) [38] con personas españolas adultas con problemas de salud mental. Por lo tanto, esta aceptable consistencia interna indicó que los 13 ítems del SDO-OB, agrupados en

cuatro áreas de la ocupación (trabajo, ocio y tiempo libre, tareas del hogar y autocuidado), cubren de forma homogénea el dominio de participación y proporcionan una información amplia sobre el mismo. Asimismo, SDO-OB demostró un patrón consistente de correlaciones con las puntuaciones del ACS, que reflejan el dominio de la participación según la CIF [20,39]. En este sentido, nuestra investigación sugiere que el SDO-OB puede proporcionar una perspectiva amplia del dominio de participación, en comparación con la mayoría de las herramientas de valoración utilizadas hasta ahora [13,14,18,40,41]. Finalmente, el sumatorio de la satisfacción con la participación y el sumatorio del nivel de participación demostraron una correlación "moderada", similar a los hallazgos del estudio de Vidaña-Moya et al. (2020) [38] en población española para la validación del SDO-OB dentro del ámbito de la salud mental. Por lo tanto, nuestro estudio sustentó que, a mayor nivel de participación, mayor satisfacción, y viceversa. Desde este punto de vista, las intervenciones centradas en aumentar los niveles de participación podrían iniciar una espiral de retroalimentación ascendente que condujera a un aumento de los niveles de satisfacción, promoviendo a su vez la continuación y el aumento de los niveles de participación, lo que de nuevo conduciría a un aumento de la satisfacción [42].

Igualmente, se encontró una correlación positiva entre el nivel de participación mantenida tras el ictus medido con el ACS y el sumatorio del nivel de participación a partir del SDO-OB. Con relación a la hipótesis planteada por los autores de nuestro artículo, los resultados confirmaron que aquellos que habían experimentado un menor porcentaje de cambio en relación con su nivel de participación previo al ictus, según el ACS, eran los que tenían niveles más altos de nivel de participación medido con el SDO-OB. Según la hipótesis previa, no se esperaba ninguna relación entre la participación mantenida medida con el ACS y la puntuación de satisfacción del SDO-OB. Sin embargo, los resultados de la investigación revelaron correlaciones "moderadas" entre las dos variables, lo que indica una posible asociación entre el nivel de participación y la satisfacción con la participación. Es importante señalar que, correlación no implica causalidad, y se necesita continuar investigando para comprender plenamente la naturaleza de esta relación. Asimismo, estos resultados sugieren que otros factores, como el estilo de vida individual y el estado de salud, pueden desempeñar un papel en la interacción entre la participación mantenida y la satisfacción con la participación [43]. Aunque estudios anteriores habían demostrado la capacidad del SDO-OB para discriminar entre participantes españoles sanos y con problemas de salud mental [38], supervivientes de un ictus árabes [44], solicitantes de asilo en Dinamarca [45] y entre personas

mayores suecas dentro y fuera de los servicios sanitarios [46]. Nuestro artículo ha sido la primera investigación que demostró la capacidad de la herramienta SDO-OB para discriminar dentro de un grupo de supervivientes españoles de un ictus, discerniendo si necesitaban o no del apoyo de un cuidador para la participación en actividades cotidianas.

El estudio transversal en supervivientes de un ictus residentes en España, que presentaban un alto nivel funcional al menos 6 meses después del ictus, incluyó las herramientas de valoración IPAQ-SF y SDO-OB para contribuir al análisis de la relación entre los niveles de actividad física y participación. En este sentido, encontró correlaciones "fuertes a moderadas" entre las subvariables de AF medidas con un dispositivo de monitorización y la participación, así como correlaciones "moderadas a débiles" entre la AF reportada por un cuestionario autoinformado y la participación. En concreto, los hallazgos de este estudio han confirmado la hipótesis en la cual los supervivientes de un ictus con un alto nivel funcional y mayores niveles de AF, son los que presentaban mayores niveles de participación [47,48]. En este sentido, se apoya la importancia de la relación entre los niveles de AF y la vuelta a la participación y la adaptación a la vida después del ictus [49], situación que contribuye a una menor dependencia y, por tanto, a un menor gasto sanitario [50].

Cabe destacar que, las asociaciones más relevantes se encontraron entre las variables de AF y la participación en actividades instrumentales de la vida diaria (p. ej., ir de compras o limpiar la casa). Por lo tanto, se refuerza la idea de que la participación activa en actividades de la vida diaria implica un gasto energético [51]. En este sentido, la participación activa podría contribuir potencialmente a aumentar los niveles de AF y, por tanto influir positivamente en la reducción de los factores de riesgo asociados a una conducta sedentaria [27,52-54], especialmente en supervivientes de un ictus con un alto nivel funcional. Por el contrario, es lógico que la participación en actividades de ocio (p. ej., ir al cine o tomar un café) o el nivel de satisfacción con la actividad, mostraron una asociación menor con el nivel de AF, teniendo en cuenta la tendencia de los supervivientes de un ictus a reducir las actividades de ocio que físicamente les requiere mayor exigencia y destinar más tiempo a un ocio sedentario [55-57]. No obstante, se necesitan más estudios para determinar las relaciones multifactoriales entre otras variables como la situación emocional, el miedo a las caídas, el entorno familiar y su importancia en el estilo de vida de los supervivientes de un ictus [1,11,29,57,58]. Desde el punto de vista de las relaciones entre la participación y la actividad física, la fuerte correlación encontrada entre SDO-OB y las subvariables objetivas de AF (p.ej., media de pasos/día y Kcal/día) refuerza los datos

aportados por el estudio de Sullivan et al. (2014)[59] en supervivientes de un ictus de más de 6 meses de evolución. Concretamente, esta relación implica que disponiendo de los datos de una subvariable de AF, se puede suponer el nivel de participación en actividades cotidianas que tendrá la persona superviviente de un ictus. En este sentido, las correlaciones encontradas entre los niveles de AF y participación de este estudio respaldan los hallazgos de una reciente revisión sistemática [30].

En relación a las herramientas de evaluación seleccionadas para valorar la AF, nuestro estudio encontró una "fuerte" correlación entre las subvariables Kcal/día y la media de pasos/día, así como la correlación "moderada" entre estos valores y los MET-min/semana. En este sentido, nuestra investigación respaldó el uso de estas subvariables de AF en los supervivientes de un ictus para determinar tanto el nivel de AF como la adherencia a las recomendaciones de la OMS [60-63]. No obstante, las correlaciones entre el nivel de participación y el nivel de AF fueron más precisas a través del dispositivo de monitorización de actividad Fitbit Inspire 2 que con el cuestionario autoinformado IPAQ-SF. Por lo tanto, dichos resultados respaldan que los dispositivos de monitorización proporcionan datos más fiables que los cuestionarios autoinformados [64]. Sin embargo, estos últimos son recomendables y útiles en ausencia de estos [12]. En cuanto a las herramientas de evaluación de la participación, tanto el sumatorio del nivel de participación registrado por el SDO-OB como la percepción de las actividades mantenidas proporcionada por ACS mostraron una correlación moderada. Por lo tanto, el uso de cualquiera de estas dos herramientas proporcionaría información valiosa sobre la complejidad del dominio de participación tras un ictus, reforzando las recomendaciones del uso de estas herramientas [13,65].

La presente investigación exploró las experiencias de los supervivientes de un ictus en relación a su estilo de vida y el vínculo con la realización de AF, ejercicio físico y retorno a la participación, aportando hallazgos relevantes que complementan y contribuyen a la interpretación y comprensión de los mismos.

La información aportada en relación con la AF y el ejercicio físico, se alineó con estudios previos [36], que mostraron la dificultad de volver a participar de forma activa [1] frente a los que suelen retomar los mismos tipos de AF que hacían antes del ictus [66]. De forma similar a los estudios realizados en otros países [27,67-69], esta investigación también reflejó un cambio en la percepción de la AF y el ejercicio físico después del ictus, donde las personas expresaron que pasó de ser una actividad ociosa realizada en el tiempo libre a una obligación. Cabe destacar que, este aspecto puede ser clave para entender el

desarrollo de conductas sedentarias y la no adquisición de rutinas activas [70-72] en personas supervivientes de un ictus. Concretamente, subrayando que la autoeficacia y la experiencia previa pueden contribuir a mejorar la adherencia a la AF y el ejercicio físico posterior al ictus [73]. Asimismo, los participantes compartieron sus propuestas para adaptar la realización de AF y el ejercicio físico a su capacidad funcional actual, de forma similar a lo expuesto en otro estudio [74]. En este sentido, este artículo profundizó en las estrategias adoptadas por los participantes para hacer frente a este aumento de su esfuerzo percibido, describiendo los procesos de evitación, modificación y sustitución de actividades. Cabe destacar que, estos hallazgos ayudarán a promover por parte de los profesionales sanitarios una adaptación individual ajustadas a la tolerancia a la intensidad de AF de los supervivientes de un ictus, contemplando la amplia heterogeneidad de las variables sociodemográficas y clínicas que presentan estas personas [35].

Asimismo, fue relevante comprender las razones que empujan a la persona a reanudar, adaptar o iniciar la AF y el ejercicio físico dado que la mayoría de los participantes no alcanzaron las recomendaciones de AF de la OMS [24,75], a pesar de contar con factores facilitadores de la AF. En este sentido, destacaron factores como las barreras arquitectónicas de la ciudad y los factores meteorológicos y ambientales como la lluvia o la temperatura[1], lo que se reflejó en las narrativas de los participantes que residían en 24 ciudades de diferentes regiones de España con climas muy diversos. Cabe destacar que, esta investigación puso de manifiesto la naturaleza multifactorial de la toma de decisiones en relación con la AF y el ejercicio físico en los supervivientes de un ictus, describiendo la ambivalencia de los aspectos personales (p.ej., satisfacción, afinidad, relevancia o importancia como válvula de escape frente a inseguridad y pereza) a la hora de incorporar el ejercicio físico a sus vidas. Como han señalado previamente otros autores, la promoción de la AF tras un ictus requiere evaluar la motivación y la capacidad de integrarla en las intervenciones [69,76]. Los participantes de este estudio, identificaron factores que consideraban relacionados con la realización de AF y el ejercicio físico (p.ej., persona, entorno y comportamiento), en consonancia con hallazgos previos [77]. A la luz de los hallazgos de esta investigación, parece necesario seguir promoviendo un cambio de paradigma en el que se promuevan pautas individualizadas para que la AF se realice fuera del ámbito sanitario, en un entorno normalizado [9,78,79].

No obstante, los participantes informaron de la necesidad de establecer una preparación física y mental previa a la realización de AF y ejercicio físico, lo que también fue reflejado anteriormente por otros autores como estrategia de autorregulación,

mediante la anticipación y superación de barreras [77]. Asimismo, los participantes describieron las formas en que han adaptado la realización de AF, demostrando un proceso de resiliencia y resolución de problemas, lo que se considera una capacidad personal de adaptación más allá de las secuelas del ictus [77]. Cabe destacar que, hasta la fecha, la mayoría de las investigaciones se han centrado en el desarrollo de planes de intervención para aumentar el nivel de AF, pero descuidando estos aspectos, entre los que destacan la autoeficacia y el autoconcepto, o las expectativas de resultados [36,69]. Finalmente, esta investigación mostró las diferentes experiencias de cansancio y fatiga física y mental en función de la percepción del gasto energético. Concretamente, esta investigación mostró la necesidad de tiempos de descanso diurnos y nocturnos y la conciencia de los límites como estrategias de afrontamiento en línea con estudios previos [80].

Los hallazgos en relación con, la experiencia de volver a participar después de haber sufrido un ictus hace más de seis meses, resaltaron los factores personales y sociales que han condicionado esta experiencia. Cabe destacar que, el estudio mostró que, tras el ictus el factor tiempo es secundario. Por el contrario, se evidenció que en el retorno a la participación hay una influencia individual multifactorial, entre los que destacaron el individuo y la familia, similar a estudios previos [18,55,81]. No obstante, aunque el paso del tiempo influyó en la recuperación funcional progresiva, no siempre implicó una vuelta a la participación a todos los niveles [1,82]. Según los resultados de la presente investigación, dependieron de las particularidades de cada actividad, de las preferencias individuales y de las influencias sociales y ambientales, así como del estilo de vida antes y después del ictus, del mismo modo que se recoge en una reciente revisión sistemática [83].

En concreto, los participantes describieron cómo la experiencia personal les ha proporcionado una lección de aprendizaje vital que les condicionó significativamente. Estos hallazgos pusieron de manifiesto, la relevancia del contexto emocional de la persona, proceso mediado por la capacidad de aceptación y adaptación, independientemente de las secuelas [84]. En particular, los resultados encontrados parecen estar en consonancia con estudios previos de una reciente revisión sistemática, que mostró que la motivación intrínseca y la actitud posterior al ictus tenían un claro impacto sobre la persistencia en la reanudación de la participación [11], sumado al enriquecimiento de las experiencias previas [43,85].

Cabe destacar que, los participantes del estudio describieron su participación actual comparándola con su estilo de vida anterior al ictus, así como su escala actual de

prioridades. Dicha información, se recopila a través de la historia ocupacional [20] del superviviente de un ictus, y la identificación de actividades significativas, pasando ambas frecuentemente desapercibidas [43,86,87]. Igualmente, los resultados mostraron que la persona hace una valoración del coste-beneficio de participar en cada una de las actividades, con especial énfasis en su capacidad de adaptación, arrojando luz sobre la complejidad de la situación vivida, en línea con estudios cualitativos previos [55] .

Asimismo, los participantes focalizaron su narrativa sobre las actividades realizadas en casa y en el tiempo libre, los estudios y el trabajo, y la capacidad para desplazarse, a pesar de que estos no siempre son objetivos prioritarios en el plan de rehabilitación [9]. Por lo tanto, se evidenció la necesidad de adaptarse a las necesidades y demandas de la persona [88,89] por su alto potencial de adherencia en el proceso de retorno a la participación [18,90-92].

La capacidad para desplazarse ha sido ya evaluada previamente, pero sin especial relación sobre las actividades que posibilita [1,93], siendo clave según los participantes de esta investigación. En este sentido, destacaron la sensación de libertad e independencia de los otros que les proporciona la posibilidad de desplazarse, en línea con estudios anteriores [89]. Cabe destacar que, en cuanto a estas relaciones interpersonales, los participantes destacaron la importancia de la familia [94], sin mencionar el rol del cuidador [95]. Pero si a la pareja, donde encontraron restricciones en las relaciones íntimas, escasamente comentadas en otros estudios [96,97], planes de intervención [96,97] y guías clínicas [9]. En ese sentido, el presente estudio aportó resultados sobre la búsqueda de alternativas fuera del círculo familiar, siendo claramente influyentes [11] y facilitadores del retorno a la participación tras un ictus [28,89]. Sin embargo, este estudio reveló la dependencia en el desarrollo de roles en la vida social dependiendo del estilo de vida previo de la persona y de su actitud actual.

7.2. Implicaciones clínicas

A continuación, se ha considerado necesario reflejar las implicaciones clínicas de los hallazgos de la investigación expuesta en la presente Tesis Doctoral.

- Es necesario establecer una colaboración interdisciplinar en la práctica clínica, basada en la existente interrelación entre los niveles de AF y participación de los supervivientes de un ictus.
- Es imprescindible realizar una selección cuidadosa de las herramientas de valoración y momentos óptimos para su administración, para captar los cambios en la AF y la participación.
- La correcta identificación de las variables de la AF permite establecer una adecuada evaluación de los efectos de la AF en la salud, adherencia a las recomendaciones de la OMS e identificar predictores significativos de inactividad física.
- Las personas supervivientes de un ictus con alto nivel funcional que realizan una adecuada cantidad de actividad física son las que alcanzan mayores niveles de participación en actividades de la vida cotidiana.
- Los planes de intervención para los supervivientes de un ictus deben considerar la contribución a un estilo de vida saludable que supone la realización de las actividades instrumentales de la vida diaria debido a su correlación con el nivel de AF.
- El diseño de planes de intervención para personas que tuvieron un ictus hace más de 6 meses, que presentan independencia en la marcha, y no tienen alteraciones cognitivas ni de comunicación, deben contemplar la correlación entre los niveles de AF y el retorno a la participación en actividades de la vida cotidiana en su entorno natural.
- El dispositivo de monitorización Fitbit Inspire 2 y el cuestionario autoinformado IPAQ-SF, son herramientas de valoración adecuadas para obtener información sobre las subvariables como Kcal/día, media de pasos/día y METs/min/semana.
- La herramienta de valoración SDO-OB y ACS, son adecuadas para aportar información sobre la participación de personas supervivientes de un ictus.

- IPA-SF es una herramienta de valoración de la AF con buenas propiedades psicométricas en supervivientes de un ictus, que refuerza la recomendación de su uso por el reciente consenso de expertos, como herramienta de cribado para evaluar el cumplimiento de las recomendaciones de AF de la OMS.
- En ausencia de dispositivos de monitorización objetivos en el contexto clínico, es posible obtener datos adecuadamente correlacionados con parámetros objetivos administrando el IPAQ-SF en supervivientes de un ictus.
- Se recomienda complementar los parámetros de AF aportados por el IPAQ-SF con datos registrados por dispositivos de monitorización, así como información cualitativa para comprender los factores que influyen en los niveles de AF en los supervivientes de un ictus.
- SDO-OB es una herramienta de evaluación sencilla, que permite recoger información relevante sobre la participación de los supervivientes de un ictus y su satisfacción con dicha situación.
- SDO-OB es capaz de detectar cambios en el nivel de participación y satisfacción de los supervivientes de un ictus, aportando información cualitativa basada en la percepción de la persona sobre las barreras y facilitadores que condicionan la participación de gran relevancia para las evaluaciones de las intervenciones en Terapia Ocupacional.
- SDO-OB tiene una buena fiabilidad intraobservador, lo que indica la estabilidad de las respuestas a SDO-OB cuando las recoge el mismo evaluador. Dispone de puntos de corte del error estándar de la media y mínimo cambio detectable de gran relevancia clínica y de investigación para comprender el impacto de las intervenciones u otros factores condicionantes.
- La realización de AF y ejercicio repercuten de forma diferente en cada persona, dependiendo de la experiencia previa y de la situación actual. En la readaptación de la AF debe tenerse en cuenta la influencia de los factores individuales y ambientales.
- Los supervivientes de un ictus en España tienen experiencias relacionadas con la AF similares a las de otros países, por lo que el éxito de la adherencia a la prescripción de AF y ejercicio depende de la percepción y preferencias de cada persona.

- La marcha es la actividad más útil y eficaz para la realización de actividades comunitarias, sobre la que se deberían diseñar soluciones y planes de intervención.
- Deben tenerse en cuenta las influencias multifactoriales, para fomentar el retorno a la participación en personas supervivientes de un ictus. Siendo clave la historia ocupacional previa al ictus, dado que el retorno a la participación no se produce en todas las personas de la misma manera a pesar de presentar secuelas leves tras haber sufrido un ictus.

7.3. Referencias

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CAPÍTULO 8. LIMITACIONES

A continuación, se describirán las principales limitaciones encontradas a lo largo del desarrollo de las investigaciones que han dado lugar a los artículos que componen esta Tesis Doctoral.

En primer lugar, en relación con la propuesta centrada en sintetizar toda la literatura existente en cuanto a la relación entre los niveles de AF y participación ***artículo 1*** los 23 estudios prospectivos seleccionados presentaron una amplia heterogeneidad en relación al diseño metodológico de los estudios, objetivos de investigación, propiedades psicométricas de las herramientas de valoración utilizadas. Asimismo, se encontraron ciertas incoherencias entre las variables y subvariables de AF y participación, las herramientas de valoración seleccionadas y los momentos de administración, así como limitados datos proporcionados. En este sentido, el metaanálisis sólo pudo realizarse con siete estudios. Además, las correlaciones observadas entre las variables AF y participación dependieron directamente de las herramientas de evaluación utilizadas y del impacto de la intervención, siendo por tanto esencial interpretar estos hallazgos con cautela. Asimismo, la posible colinealidad entre las variables debido al gasto energético que supone la realización de cualquier actividad de la vida diaria puede llevar a una sobrestimación de esta correlación. Por lo tanto, los resultados de esta revisión sistemática con metaanálisis deben ser interpretados con prudencia y será necesario actualizarlos en un futuro, cuando se dispongan de una mayor cantidad de estudios que incluyan un marco estandarizado para la metodología de evaluación y los tiempos de seguimiento en los supervivientes de un ictus.

Cabe destacar que los estudios expuestos en los artículos ***2, 3 ,4 ,5 y 6*** no dispusieron inicialmente con ningún tipo de financiación para su diseño y elaboración, contando con la participación voluntaria, fuera de su horario laboral, de los profesionales colaboradores que pertenecían a la red de contactos de la investigadora principal y doctoranda de la presente Tesis Doctoral. Dicha situación ocasionó que el nivel de implicación y tiempo destinado de los profesionales colaboradores fluctuara durante la elaboración de estos estudios, sumado a situaciones personales como embarazos y cambios de trabajo. Así mismo el reclutamiento de la muestra, a pesar de ser propuesto a todas aquellas personas que cumplían los criterios de elegibilidad, dependió

principalmente de estos profesionales colaboradores y la voluntariedad en la participación de las personas supervivientes de un ictus, sus familiares y/o cuidadores principales quedando registrado tanto el motivo personal (p. ej., depresión, problemas familiares o poco tiempo disponible) o clínico (p. ej., ingreso médico o fallecimiento) por el cual no quisieron participar o abandonaron el estudio.

Desde el punto de vista de viabilidad tanto económica como logística, el diseño metodológico de los estudios expuestos en los ***artículos 2, 3 y 4*** se centró en la selección de herramientas de valoración autoinformadas a excepción de la inclusión del dispositivo de monitorización Fitbit Inspire 2. Estos dispositivos fueron prestados por el grupo de investigación MOTUS de la Universidad San Jorge. Asimismo, no se realizó una revisión sistemática previa para la selección de las herramientas de valoración más adecuadas en relación a cada una de las variables, incurriendo en un sesgo de repetición puesto que la selección se sustentó en las herramientas más utilizadas por la actual literatura y experiencia clínica de la doctoranda. No obstante, se intentó controlar este sesgo con un estudio piloto previo en el que participaron 7 profesionales colaboradores con amplia experiencia clínica.

Cabe destacar que el uso de la aplicación *Prevent for Work* ayudó en gran medida a la gestión de la recopilación de los datos por parte de los profesionales colaboradores pertenecientes a los diferentes centros. Sin embargo, a pesar de realizar a estos profesionales colaboradores una formación previa sobre el uso de esta aplicación y establecer un seguimiento de los registros para solventar las incidencias, en diversos momentos se perdieron datos por un registro incorrecto, y hubo dificultades con el acceso a dicha aplicación. Asimismo, la extracción del alto volumen de datos de la amplia muestra para posteriormente ser analizados fue una tarea muy compleja. En este sentido, una situación similar ocurrió con el uso del dispositivo de monitorización Fitbit Inspire 2, el cual requirió de la instalación de una aplicación en un dispositivo móvil compatible, la vinculación correcta del dispositivo al móvil y la actualización diaria de los datos por parte de los participantes. A pesar de un seguimiento personalizado por parte de la doctoranda y los profesionales colaboradores, hubo diversas incidencias que implicaron la perdida de datos.

Es necesario tener en cuenta que a pesar de que los estudios de los **artículos 2, 3, 4, 5, y 6** que forman esta Tesis Doctoral han contado con una amplia muestra perteneciente al proyecto de investigación multicéntrico Part&Sed-Stroke, los criterios de elegibilidad de la muestra fueron muy exigentes. En este sentido, los participantes

formaban parte de un segmento de la población superviviente de un ictus que no presentaban alteraciones de las funciones cognitivas ni de la comunicación y que hacía más de 6 meses que han tenido un ictus. La gran mayoría de las personas eran capaces de caminar y no dependían de la figura de un cuidador para el desempeño de las tareas cotidianas. Por lo tanto, los resultados de los estudios aquí expuestos sólo dan respuesta a la situación de este segmento de los superviviente de un ictus y no pueden extrapolarse a supervivientes de un ictus en una fase más temprana o con mayores secuelas funcionales como alteraciones en la comunicación o funciones cognitivas, siendo necesario en futuros estudios ampliar dichos criterios de elegibilidad.

En relación al estudio expuesto en el ***artículo 2,*** la estabilidad test-retest pudo estar influenciada por factores meteorológicos o variaciones naturales en la AF semanal que podrían haber impactado en los niveles de AF autoinformados de la herramienta de valoración IPAQ-SF, a pesar de haber sido administrada en igualdad de condiciones y habiendo descartado o dado por perdidos aquellos los datos referentes a los participantes que no cumplieron esta condición.

La elaboración de los estudios cualitativos plasmados en los ***artículos 5 y 6*** requirió del uso de nuevas tecnologías como la videollamada a través de la plataforma TEAMS con tal de solventar la recogida de la información de la muestra ampliamente distribuida por toda la geografía española. Dicha necesidad tecnológica para realizar las entrevistas acotó los criterios de inclusión de la muestra a aquellas personas con disponibilidad de dispositivos móviles y con adecuadas habilidades tecnológicas. En este sentido, es necesario destacar que a pesar de que ambos estudios contaron con una amplia muestra para tratarse de un estudio de diseño cualitativo, los participantes de ambos estudios fueron los mismos, a pesar de recoger una pregunta de investigación y entrevistas semiestructuradas con diferentes preguntas. Por lo tanto, los resultados de ambos estudios no se pueden extrapolar a todos los supervivientes de un ictus, debido a la naturaleza de la pregunta de investigación, el diseño cualitativo seleccionado y las características de la muestra.

Por último, las limitaciones de esta Tesis Doctoral no sólo abarcan las limitaciones presentadas en la elaboración de cada uno de los estudios, sino que deben incluirse las limitaciones personales de los investigadores entre las que se encuentran la conciliación familiar y laboral que raramente se contemplan o comentan al respecto.

CAPÍTULO 9. FUTURAS LÍNEAS DE INVESTIGACIÓN

Tras la realización de los estudios de investigación que componen la presente Tesis Doctoral, se plantean las siguientes futuras líneas de investigación:

- Conocer las propiedades psicométricas de los dispositivos de monitorización de la AF de bajo coste y alta accesibilidad en la población superviviente de un ictus, como la pulsera de actividad Fitbit Inspire 2, tanto para su uso a nivel de investigación como su aplicabilidad en el ámbito clínico.
- Continuar analizando las propiedades psicométricas de la herramienta de valoración SDO-OB en personas supervivientes de un ictus, como la fiabilidad interobservador. Asimismo, elaborar un análisis cualitativo que permita profundizar en las causas que impiden el retorno a la participación e identificar los factores que pueden ayudar a restaurar la participación, en términos de nivel de satisfacción con la participación y equilibrio de la participación.
- Establecer un consenso de expertos en relación con las variables y subvariables del dominio de la participación y las herramientas más adecuadas en función de sus propiedades psicométricas para su registro. Esto permitirá establecer un marco estandarizado para la metodología de evaluación y los tiempos de seguimiento en los supervivientes de ictus, contemplando su situación clínica. De esta forma se reducirá la heterogeneidad en los estudios y se facilitará la síntesis de los datos en futuros estudios de revisión sistemática con metaanálisis.
- Explorar la variable de dolor y sus relaciones multifactoriales en personas supervivientes de un ictus hace más de 6 meses con buen nivel funcional.
- Analizar la cantidad y calidad del sueño, tanto autoinformada como registrada objetivamente a través de dispositivos de monitorización en personas supervivientes de un ictus con buen nivel funcional.
- Llevar a cabo un estudio de diseño transversal para analizar las relaciones multifactoriales e identificar los principales factores predictores de un estilo de vida menos saludable, ligados al sedentarismo y al no retorno a la participación en actividades cotidianas en personas supervivientes de un ictus con buen nivel funcional. Concretamente, contemplando la influencia de otros factores como la

velocidad de la marcha, las secuelas del ictus, años de evolución, entorno y apoyo social, y factores personales o clínicos como el estado de ansiedad o depresión, la cantidad y calidad del sueño o el dolor.

- Analizar la evolución natural a lo largo de 6 y 12 meses de las personas supervivientes de un ictus que tuvieron el ictus hace más de 6 meses y presentan buena capacidad funcional para contemplar las relaciones multifactoriales que condicionan su estilo de vida (p. ej., factores sociodemográficos, clínicos, así como niveles de AF y participación).
- Elaborar una investigación diseñada específicamente para investigar la correlación entre todas las subvariables del dominio AF y participación, tanto transversal como longitudinalmente en personas supervivientes de un ictus con diferentes niveles funcionales, en los diferentes momentos de su proceso de evolución; es decir, contemplando tanto los primeros 6 meses, como los meses y años posteriores.
- Examinar la influencia de la necesidad de la figura de un cuidador para participar en las actividades cotidianas, así como el perfil individual que presenta este cuidador. Los datos de este estudio contribuirían a entender por qué aquellas personas supervivientes de un ictus que tenían un cuidador, tenían niveles más bajos de participación y satisfacción y una situación de infraocupación en relación con el equilibrio de la participación según los datos aportados por SDO-OB.
- Analizar el estilo de vida de los cuidadores principales de personas supervivientes de un ictus, en relación con su nivel de AF y participación, y posibles factores de riesgo modificables de sufrir un ictus, puesto que el desempeño de este rol de cuidador puede tener un impacto sobre sus vidas.
- Entender la experiencia individual de las personas supervivientes de un ictus durante los primeros 6 meses con alta capacidad funcional (marcha independiente y sin alteraciones en las funciones cognitivas ni de comunicación), en cuanto a la realización de actividad y ejercicio físico, así como el retorno a la participación.
- Comprender la experiencia de AF y ejercicio físico y retorno a la participación en el segmento de supervivientes de ictus con grandes secuelas y por tanto más dependientes en su vida cotidiana, tanto durante los primeros 6 meses como posteriormente.
- Extrapolar el diseño del proyecto de investigación multicéntrico Part&Sed-Stroke a un proyecto de investigación multicéntrico que involucre la participación

de varios países, con tal de analizar las diferencias en relación con los factores socioculturales y ambientales (p.ej., horas de luz, temperatura, lluvia).

- Analizar el impacto de la educación para la salud sobre los estilos de vida saludables ligados a la reducción del sedentarismo o incremento en la participación en actividades cotidianas a través de un programa ERASMUS+ destinado a la transferencia del conocimiento sobre la prevención primaria, secundaria y terciaria tanto a profesionales sanitarios, personas sanas, como supervivientes de un ictus y sus familiares.
- Llevar a cabo un ensayo controlado aleatorizado basado en una intervención que impacte sobre el estilo de vida, especialmente sobre las variables de AF y participación que contemple las relaciones multifactoriales y los factores predictores previamente identificados que influyen sobre dicho estilo de vida en personas supervivientes de un ictus.

CAPÍTULO 10. CONCLUSIONES

- En los supervivientes de un ictus existe una correlación positiva moderada entre el tiempo de AF y la participación en las actividades de la vida diaria en participantes durante los primeros 6 meses después del ictus, y entre el tiempo de AF y la participación en todas las actividades de la vida cotidiana en participantes más allá de los 6 meses posteriores al ictus.

- Mientras que la AF mostró mejoras significativas en el tiempo, la participación sólo mostró una tendencia. Es decir, los niveles de AF en supervivientes de un ictus parecen aumentar en las primeras semanas o meses en comparación con los niveles de participación, que necesitaron más tiempo para mostrar mejoras significativas.

- Existe una gran heterogeneidad en las investigaciones realizadas en supervivientes de un ictus focalizadas en analizar el nivel de AF y participación. Concretamente en cuanto al diseño del estudio, los objetivos de la investigación, las propiedades psicométricas de las herramientas de evaluación, y momentos de su administración.

- La herramienta de valoración IPAQ-SF demostró una adecuada validez aparente y de contenido. En este sentido, la administración de IPAQ-SF en supervivientes de un ictus debe ser realizada por evaluadores con experiencia en la asistencia clínica de estas personas y previamente entrenados utilizando un protocolo de entrevista estandarizado que debe contemplar la casuística de estas personas.

- IPAQ-SF demostró una adecuada validez de constructo, presentando correlaciones “moderadas” a “fuertes” con la pulsera de monitorización de actividad Fitbit Inspire 2, y correlaciones “débiles” a “moderadas” con el test de velocidad de la marcha 6MTW. Además, la estabilidad test-retest IPAQ-SF fue de “moderada” a “excelente”.

- IPAQ-SF es un cuestionario autoinformado de bajo coste y rápida administración, válido para el cribado de los niveles de AF y el cumplimiento de los niveles de AFM recomendados por la OMS de supervivientes de ictus con funcionalidad física y cognitiva preservada tanto en contextos clínicos como de investigación.

- La herramienta de valoración SDO-OB presentó una consistencia interna aceptable.

- SDO-OB presentó una validez convergente aceptable demostrando una correlación "moderada" entre el sumatorio de los niveles de participación y el sumatorio de la satisfacción con la participación, y los ítems de EQ-5D-5L y ACS que evaluaron los mismos constructos.

- SDO-OB discriminó entre grupos con y sin cuidadores y no tuvo efectos de suelo o techo. Además, la fiabilidad test-retest fue buena para el sumatorio del nivel de actividad y el sumatorio de la satisfacción con la actividad.

- Las buenas propiedades psicométricas de la versión española del SDO-OB indican que puede ser un instrumento de referencia para abordar el nivel de actividad, la satisfacción y el equilibrio en la participación en actividades en personas supervivientes de un ictus.

- El nivel de AF autoinformada a través IPAQ-SF y monitorizado a través del dispositivo Fitbit Inspire 2 en supervivientes de ictus con un alto nivel funcional tiene una correlación bilateral con sus actividades instrumentales de la vida diaria mantenidas medidas con ACS y su nivel de participación medido con SDO-OB.

- El restablecimiento de los niveles de participación tras un ictus no depende exclusivamente de los niveles de AF, pero parece ser uno de los factores más relevantes.

- Las personas supervivientes de un ictus con un buen nivel funcional que residen en España destacaron la perspectiva individual sobre la readaptación a la AF y el ejercicio físico. Destacaron la importancia de las secuelas que limitan esta readaptación, las preferencias individuales, el estilo de vida activa previo, así como las múltiples influencias del entorno sobre este comportamiento cuando las secuelas del ictus no limitan la deambulación y por tanto la posibilidad de movimiento.

- El retorno a la participación tras un ictus es una experiencia individual compleja con influencias multifactoriales. Entre los factores más relevantes que influyen sobre este proceso se encuentran la historia ocupacional previa al ictus, la percepción de uno mismo en el transcurso de la recuperación, la capacidad de aceptar la situación y adaptarse apoyándose en el contexto familiar y social, así como la búsqueda de formas alternativas de adaptación al entorno.

CAPÍTULO 11. ANEXOS

Se adjuntan los siguientes anexos:

Anexo 4. Artículos de protocolos (revisión sistemática con metaanálisis y proyecto PartSed-Stroke).

Anexo 4. *Artículos de protocolo*

(Revisión sistemática con metaanálisis y proyecto Part&Sed-Stroke).

Artículo: Relationship between Participation in Daily Life Activities and Physical Activity in Stroke Survivors: A Protocol for a Systematic Review and Meta-Analysis

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Healthcare (Basel). 2023 Jul 30;11(15):2167
(Editorial: MDPI) Q2, JIF:2.4
DOI: 10.3390/healthcare11152167.

Citar como: *de Diego-Alonso C, Blasco-Abadía J, Buesa-Estéllez A, Giner-Nicolás R, López-Royo MP, Roldán-Pérez P, Doménech-García V, Bellosta-López P, Fini N. Relationship between Participation in Daily Life Activities and Physical Activity in Stroke Survivors: A Protocol for a Systematic Review and Meta-Analysis. Healthcare (Basel). 2023 Jul 30;11(15):2167. doi: 10.3390/healthcare11152167. PMID: 37570407; PMCID: PMC10419119.*

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Protocol

Relationship between Participation in Daily Life Activities and Physical Activity in Stroke Survivors: A Protocol for a Systematic Review and Meta-Analysis

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Abstract: Stroke survivors undertake low levels of physical activity and participation in daily life activities, but the correlation between these two domains still carries some degree of uncertainty. This systematic review and meta-analyses-based data synthesis will aim to describe and estimate the relationship between participation in daily life activities and physical activity in stroke survivors. Six databases (MEDLINE/PubMed, Web of Science, Scopus, PEDro, SPORTDiscus, and Rehabilitation & Sport Medicine Source) will be searched. Studies assessing participation alongside physical activity levels in adult stroke survivors in English or Spanish will be included. The study selection, assessment of the risk of bias, and data extraction will be conducted independently by two investigators. If available, correlation values between physical activity and participation outcomes will be extracted. The Hedges–Olkin method will be used for pooling correlation values between participation and physical activity measures. Subgroup analyses will be performed according to the time elapsed since the stroke (i.e., ≤6 months and >6 months). This will be the first systematic review with a meta-analysis to provide information on the relationship between physical activity and participation in stroke survivors. Findings are likely to inform the design of health prevention protocols and the development of healthy behavior change interventions.

Keywords: physical activity; participation; activities of daily living; stroke; relationship; protocol; systematic review; meta-analysis

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Citation: de Diego-Alonso, C.; Blasco-Abadía, J.; Buesa-Estéllez, A.; Giner-Nicolás, R.; López-Royo, M.P.; Roldán-Pérez, P.; Doménech-García, V.; Bellosta-López, P.; Fini, N. Relationship between Participation in Daily Life Activities and Physical Activity in Stroke Survivors: A Protocol for a Systematic Review and Meta-Analysis. *Healthcare* **2023**, *11*, 2167. https://doi.org/10.3390/healthcare11152167

Academic Editor: Mirja Hirvensalo

Received: 1 July 2023
Revised: 20 July 2023
Accepted: 24 July 2023
Published: 30 July 2023

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1. Introduction

Stroke is the second leading cause of death in developed countries, and, according to World Health Organization (WHO) projections, one in four people will suffer a stroke throughout their lifetime [1]. Estimations indicate a significant rise in the number of stroke survivors worldwide by 2040–2050 [2–8]. Stroke is currently the third leading cause of disability worldwide [8] as it often leads to serious sequelae including sensory–motor, cognitive, and emotional impairments [9], which require neurorehabilitation [10]. For example, two-thirds show difficulty in walking independently, which is maintained beyond three months post-stroke [11]. These post-stroke sequelae generate limitations in activities and restrict participation in daily life activities such as social or leisure activities [12,13]. While immediate post-stroke sequelae might be inevitable, the subsequent sedentary lifestyle often observed in stroke survivors is believed to be modifiable [14]. Therefore, participation and physical activity (PA) are key targets for healthy lifestyles for stroke survivors.

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as a person's involvement in life situations, which means an interaction between the individual's health condition and contextual factors (i.e., environmental and personal factors) [15,16]. In addition, participation implies the performance of meaningful activities, habits, role performance, and social and community involvement [17]. Restoration of participation and functional levels is the main goal in occupational therapy [18]. However, the evidence regarding factors influencing the recovery of participation in daily life activities is limited. Commonly work, leisure, and domestic activities are the most affected after stroke [19,20].

PA is defined by the WHO as "any bodily movement produced by skeletal muscles that requires energy expenditure"; therefore, this includes all movement during leisure time, for transport to get to and from places, or as part of a person's work and domestic duties [21]. PA can involve different intensities, such as light, moderate, and vigorous-intensity PA [21]. Following stroke, survivors are commonly inactive and have significantly increased sedentary lifestyles [22–24], spending long periods without activity, which may be related to the effects of the stroke [25]. In essence, post-stroke PA levels are lower than that recommended by the WHO for preventing diseases such as stroke [26].

It has been observed that a greater capacity for functional independence implies greater participation, with the ability to walk and drive, as well as having an extensive social network, being considered enablers [27]. However, it has been shown that despite increased physical functioning, most people continue to have participation restrictions in social and leisure [27], work [28], and housekeeping activities [29], which generates a high level of concern for stroke survivors [30].

A previous review recommended that studies must include several complementary assessment tools to globally record the level of participation and PA to establish a complete correlation between these variables [31,32]. To date, no systematic review has been conducted to synthesize the evidence on the relationship between participation and PA in stroke survivors. This review will be the first to provide key information to understanding the relationship between participation in daily activities and PA levels in the stroke survivor population.

A low level of PA is a primary risk factor for stroke recurrence, which, together with the level of participation in activities of daily living, is an indicator of the quality of life of stroke survivors. Additionally, a low level of PA is associated with a higher degree of dependency, a situation that impacts healthcare expenditure due to resource requirements [33]. Considering the WHO's demand to seek solutions [34], it is imperative to update and synthesise the current information available and produce a meta-analysis on the relationship between PA levels and participation. To date, only a separate analysis of these data is available in the stroke population [12,35–39]. The results of this study will allow to understand whether people with higher levels of participation in activities of daily living are those who are less sedentary, or, on the contrary, if participating in activities of daily living does not correlate with reaching recommended levels of PA. Therefore, this systematic review with a meta-analysis may or may not demonstrate the need to target participation in activities of daily living, along with PA levels for secondary prevention in stroke survivors.

Objectives

The general objective of this systematic review and meta-analysis is to provide a comprehensive understanding of whether there is a relationship between levels of PA and participation in individuals who have experienced a stroke. However, this review and meta-analysis is not intended to evaluate the effectiveness of interventions.

This systematic review also aims to comprehensively gather and synthesize all available scientific evidence reporting PA levels and participation in the population of stroke survivors. This will include a synthesis of the most used assessment tools and reported variables.

Additionally, the meta-analysis aims to quantitatively estimate potential correlations between participation in activities of daily living and PA among stroke survivors. The meta-analysis will pool data from different studies, providing a more comprehensive and

representative overview of the research evidence. It will offer a confidence interval to determine the strength of the relationship between PA and participation, and it will help clarify any potential inconsistent or contradictory findings.

2. Materials and Methods

2.1. Study Design and Registration

This protocol has been reported following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) [40] and it was registered in the International Prospective Register of Systematic Reviews (PROSPERO) database (CRD42022360711).

Given the aim and observational nature of this systematic review and meta-analysis, the research question was formulated using the PEO framework (Population: stroke; Exposure: level of PA; Outcome: level of participation) to investigate the association between specific exposures and outcomes [41,42].

2.2. Eligibility Criteria

Table 1 presents a synthesis of the inclusion and exclusion criteria that will be employed during the study selection process.

Table 1. Summary of eligibility criteria.

PEO	Inclusion Criteria	Exclusion Criteria
Population	Stroke survivors: >18 years, ≤6 months and >6 months since stroke. Study sample ≥ 10.	Transient ischemic attack, composite sample, or coexistence of other neurological disorders.
Exposition/ Outcome 1	Physical activity measures: recorded by objective diapositives and self-reported questionnaires.	Physical performance tests (e.g., 6 min walking test, 10 m walk test, treadmill exercise test).
Exposition/ Outcome 2	Participation measures: recorded by direct observational techniques and self-reported questionnaires.	Domains not covered by the occupational therapy framework.

2.2.1. Study Types

Studies with a cross-sectional or prospective design evaluating participation alongside PA levels in stroke survivors will be included. Articles with full-text available and published in a peer-reviewed journal in English or Spanish languages will be included. Furthermore, if compatible results with the research question are identified in conference proceeding abstracts, the authors will be contacted to request the full data to ensure that relevant results related to the research question are not overlooked or excluded. The search for relevant studies will not have any restrictions based on the date of publication. However, to minimize the risk of bias resulting from small sample sizes during the meta-analysis, only studies with a sample size of more than 10 participants will be included [43].

2.2.2. Participant Characteristics

Studies recruiting adult participants (≥18 years) with stroke diagnosis regardless of time since stroke or severity of stroke sequelae, the etiology, sex, or geographical location will be included. Studies with mixed populations with composite data will be excluded unless stroke data is able to be extracted separately. In addition, the population will be grouped according to time since stroke (less than or equal to 6 months and more than 6 months) for subsequent data synthesis and analysis.

2.2.3. Characteristics of the Outcome Measures

Studies reporting PA data (e.g., minutes of PA at different intensities, caloric expenditure per PA, steps, sitting/standing time) measured by objective devices (e.g., pedometers, accelerometers), self-reported questionnaires or observational tools, and degree of participation in at least at least one area of daily living activity according to the occupational therapy framework: basic activities and instrumental activities of daily living, rest and

sleep, education, work, play, leisure, or social participation [17] will be included (Table 2). Studies only including physical performance tests will be excluded, as these cannot be considered as direct indicators of PA.

Table 2. Examples of potential tools and variables related to physical activity and participation outcomes that are anticipated to be identified while conducting the review.

Exposure/ Outcome	Type of Assessment	Potential Tools and Methods	Potential Variables
Physical activity	Objective devices	Pedometers Accelerometers Fitness trackers Smartwatches Mobile applications	METs h/day Total PA (Min/day) Vigorous PA (Min/day) Moderate PA (Min/day) Walking duration (Min/day) Steps/Day Sedentary time (sitting or lying) (Min/day)
	Self-reported questionnaires	International Physical Activity Questionnaire Physical Activity Scale for the Elderly	
Participation	Direct observation	Behavioral mapping	Total Participation level (0/100) Level of Basic ADL (0/100) Level of Instrumental ADL (0/100) Level of Social participation (0/100) Level of Work Participation (0/100) Level of Leisure Participation (0/100)
	Self-reported questionnaires	Stroke Impact Scale Barthel Index Frenchay Activities Index Activity Card Sort	

Abbreviations: ADL = activities of daily living; METs = metabolic equivalents; PA = physical activity.

2.3. Data Sources and Searches

A search will be carried out in six electronic databases (MEDLINE via PubMed; Web of Science and Scopus via Web of Science, managed by the Spanish Foundation for Science and Technology; SPORTDiscus and Rehabilitation & Sport Medicine Source via EBSCOhost; and PEDro) until April 2023. Search terms will be grouped into three categories: stroke-related words, PA terms, and participation in daily life activities terms. The different search strategies used in each database are presented in Table 3. Moreover, a thorough examination of the reference lists included in the full-text articles reviewed will be conducted.

To ensure a comprehensive and robust search strategy that encompasses all relevant aspects of the topic, synonyms of terms related to the three categories were included in the search strategy. Additionally, a separate analysis of search strategies employed in previous systematic reviews focusing on participation [12,44,45] and PA [14,22,46,47] was conducted, considering that this review will be the first to encompass both domains simultaneously. Furthermore, MeSH terms, concepts, and terms utilized in the Occupational Therapy framework [17] and the ICF [48] were incorporated.

Table 3. Search strategies according to each database.

Database	Medline (Through PubMed)
Procedure	Combining the search strategy with the Boolean Operator: AND.
Stroke	("Stroke"[Mesh] OR stroke[tiab] OR "cerebrovascular accident"[tiab] OR "cerebral vascular accident"[tiab] OR "cerebral vasospasm"[tiab] OR "cerebral bleed"[tiab] OR "post stroke"[tiab] OR poststroke[tiab] OR "cerebral ischaemia"[tiab] OR "brain ischemia"[tiab] OR "brain infarct"[tiab] OR "cerebral infarct"[tiab] OR "brain haemorrhage"[tiab] OR "cerebral haemorrhage"[tiab] OR "intracerebral haemorrhage"[tiab] OR "subarachnoid haemorrhage"[tiab] OR "intracranial haemorrhage"[tiab] OR "brain hemorrhage"[tiab] OR "cerebral hemorrhage"[tiab] OR "intracerebral hemorrhage"[tiab] OR "subarachnoid hemorrhage"[tiab] OR "intracranial hemorrhage"[tiab])

Table 3. *Cont.*

Database	**Medline (Through PubMed)**
Physical Activity	("Sedentary Behavior"[Mesh] OR "sedentary time"[tiab] OR "physical inactivity"[tiab] OR "physical activity"[tiab] OR walk* OR steps OR MVPA OR MPA OR "moderate to vigorous physical" OR LPA OR LIPA OR "light intensity physical activity" OR "metabolic equivalent of task" OR "Actigraphy"[Mesh] OR "activity monitor" OR "activity tracker" OR acceleromet* OR "pedometer" OR sensewear OR sense-wear OR activPAL OR "PAL 2" OR PAL2 OR IDEEA OR actigraph* OR actiwatch* OR stepwatch OR "actical" OR "activ8" OR "apple watch" OR "googlefit" OR "movemonitor" OR "step activity monitor" OR "StepWatch" OR "axivity" OR "motion logger*" OR motionlogger* OR fitbit OR IPAQ OR "International Physical Activity Questionnaire" OR PASE OR "Physical Activity Scale for the Elderly" OR PACE OR "Physician-based Assessment AND Counselling for Exercise")
Participation	("occupational area*" OR "daily life activities"[tiab] OR "daily life activities"[tiab] OR "everyday occupations"[tiab] OR ADL[tiab] OR "activities of daily living"[tiab] OR BADL[tiab] OR "basic activities of daily living"[tiab] OR IADL[tiab] OR "instrumental activities of daily living"[tiab] OR "self-care"[tiab] OR "leisure activities"[tiab] OR "social activities"[tiab] OR "community activities"[tiab] OR "community-dwelling"[tiab] OR "activities at home"[tiab] OR "social life"[tiab] OR sleep*[tiab] OR rest[tiab] OR "Occupational habit*" OR autonomy OR independence OR "occupational balance" OR "occupational satisfaction" OR "role performance" OR "community participation" OR "social participation" OR "return to work" OR "recovery activities" OR "meaningful activities" OR "participation restriction" OR "participation satisfaction" OR "role performance" OR "community reintegration" OR "community mobility" OR "behavioral mapping" OR ACS OR "activity card sort" OR SIS OR "stroke impact scale" OR BI OR "barthel index" OR FAI OR "frenchay activities index" OR "assessment of life habits" OR LHS OR "london handicap scale" OR LIFE-H OR "assessment of life habits" OR RNLI OR "reintegration to normal living")
Filters	Language: English OR Spanish Species: Humans Publication date: All years available
Database	**Web of Science (through Web of Science, managed by the Spanish Foundation for Science and Technology)**
Procedure	Advanced search in Web of Science—All databases. Combining the search strategy with the Boolean Operator: AND.
Stroke	AB = (stroke OR "cerebrovascular accident" OR "cerebral vascular accident" OR "cerebral vasospasm" OR "cerebral bleed" OR "post stroke" OR poststroke OR "cerebral ischaemia" OR "brain ischemia" OR "brain infarct" OR "cerebral infarct" OR "brain haemorrhage" OR "cerebral haemorrhage" OR "intracerebral haemorrhage" OR "subarachnoid haemorrhage" OR "intracranial haemorrhage" OR "brain hemorrhage" OR "cerebral hemorrhage" OR "intracerebral hemorrhage" OR "subarachnoid hemorrhage" OR "intracranial hemorrhage")
Physical Activity	AB = ("Sedentary Behavior" OR "sedentary time" OR "physical inactivity" OR "physical activity" OR walk* OR steps OR MVPA OR MPA OR "moderate to vigorous physical" OR LPA OR LIPA OR "light intensity physical activity" OR "metabolic equivalent of task" OR "Actigraphy" OR "activity monitor" OR "activity tracker" OR acceleromet* OR "pedometer" OR sensewear OR sense-wear OR activPAL OR "PAL 2" OR PAL2 OR IDEEA OR actigraph* OR actiwatch* OR stepwatch OR "actical" OR "activ8" OR "apple watch" OR "googlefit" OR "movemonitor" OR "step activity monitor" OR "StepWatch" OR "axivity" OR "motion logger*" OR motionlogger* OR fitbit OR IPAQ OR "International Physical Activity Questionnaire" OR PASE OR "Physical Activity Scale for the Elderly" OR PACE OR "Physician-based Assessment and Counselling for Exercise")

Table 3. *Cont.*

Database	Medline (Through PubMed)
Participation	AB = ("occupational area*" OR "daily life activities" OR "daily life activities" OR "everyday occupations" OR ADL OR "activities of daily living" OR BADL OR "basic activities of daily living" OR IADL OR "instrumental activities of daily living" OR "self-care" OR "leisure activities" OR "social activities" OR "community activities" OR "community-dwelling" OR "activities at home" OR "social life" OR sleep* OR rest OR "Occupational habit*" OR autonomy OR independence OR "occupational balance" OR "occupational satisfaction" OR "role performance" OR "community participation" OR "social participation" OR "return to work" OR "recovery activities" OR "meaningful activities" OR "participation restriction" OR "participation satisfaction" OR "role performance" OR "community reintegration" OR "community mobility" OR "behavioral mapping" OR ACS OR "activity card sort" OR SIS OR "stroke impact scale" OR BI OR "barthel index" OR FAI OR "frenchay activities index" OR "assessment of life habits" OR LHS OR "london handicap scale OR LIFE-H OR "assessment of life habits" OR RNLI OR "reintegration to normal living")
Filters	Language: English OR Spanish Publication Years: All years available MeSH Headings: Humans
Database	**SCOPUS (through Web of Science, managed by the Spanish Foundation for Science and Technology)**
Procedure	Advanced document search. Combining the search strategy with the Boolean Operator: AND.
Stroke	TITLE-ABS("Stroke" OR stroke OR "cerebrovascular accident" OR "cerebral vascular accident" OR "cerebral vasospasm" OR "cerebral bleed" OR "post stroke" OR poststroke OR "cerebral ischaemia" OR "brain ischemia" OR "brain infarct" OR "cerebral infarct" OR "brain haemorrhage" OR "cerebral haemorrhage" OR "intracerebral haemorrhage" OR "subarachnoid haemorrhage" OR "intracranial haemorrhage" OR "brain hemorrhage" OR "cerebral hemorrhage" OR "intracerebral hemorrhage" OR "subarachnoid hemorrhage" OR "intracranial hemorrhage")
Physical Activity	TITLE-ABS("Sedentary Behavior" OR "sedentary time" OR "physical inactivity" OR "physical activity" OR walk* OR steps OR mvpa OR mpa OR "moderate to vigorous physical" OR lpa OR lipa OR "light intensity physical activity" OR "metabolic equivalent of task" OR "Actigraphy" OR "activity monitor" OR "activity tracker" OR acceleromet* OR "pedometer" OR sensewear OR sense-wear OR activpal OR "PAL 2" OR pal2 OR ideea OR actigraph* OR actiwatch* OR stepwatch OR "actical" OR "activ8" OR "apple watch" OR "googlefit" OR "movemonitor" OR "step activity monitor" OR "StepWatch" OR "axivity" OR "motion logger*" OR motionlogger* OR fitbit OR ipaq OR "International Physical Activity Questionnaire" OR pase OR "Physical Activity Scale for the Elderly" OR pace OR "Physician-based Assessment and Counselling for Exercise")
Participation	TITLE-ABS("occupational area*" OR "daily life activities" OR "daily life activities" OR "everyday occupations" OR adl OR "activities of daily living" OR badl OR "basic activities of daily living" OR iadl OR "instrumental activities of daily living" OR "self-care" OR "leisure activities" OR "social activities" OR "community activities" OR "community-dwelling" OR "activities at home" OR "social life" OR sleep* OR rest OR "Occupational habit*" OR autonomy OR independence OR "occupational balance" OR "occupational satisfaction" OR "role performance" OR "community participation" OR "social participation" OR "return to work" OR "recovery activities" OR "meaningful activities" OR "participation restriction" OR "participation satisfaction" OR "role performance" OR "community reintegration" OR "community mobility" OR "behavioral mapping" OR acs OR "activity card sort" OR sis OR "stroke impact scale" OR bi OR "barthel index" OR fai OR "frenchay activities index" OR "assessment of life habits" OR lhs OR "london handicap scale" OR life-h OR "assessment of life habits" OR rnli OR "reintegration to normal living")

Table 3. *Cont.*

Database	**Medline (Through PubMed)**
Filters	Language: English OR Spanish Publication Years: All years available
Database	**Rehabilitation & Sports Medicine Source, and SPORTDiscus with Full Text (through EBSCOhost)**
Procedure	Advanced Search. Combining the search strategy (abstract) with the Boolean Operator: AND.
Stroke	stroke OR "cerebrovascular accident" OR "cerebral vascular accident" OR "cerebral vasospasm" OR "cerebral bleed" OR "post stroke" OR poststroke OR "cerebral ischaemia" OR "brain ischemia" OR "brain infarct" OR "cerebral infarct" OR "brain haemorrhage" OR "cerebral haemorrhage" OR "intracerebral haemorrhage" OR "subarachnoid haemorrhage" OR "intracranial haemorrhage" OR "brain hemorrhage" OR "cerebral hemorrhage" OR "intracerebral hemorrhage" OR "subarachnoid hemorrhage" OR "intracranial hemorrhage"
Physical Activity	"sedentary Behavior" OR "sedentary time" OR "physical inactivity" OR "physical activity" OR walk* OR steps OR MVPA OR MPA OR "moderate to vigorous physical" OR LPA OR LIPA OR "light intensity physical activity" OR "metabolic equivalent of task" OR "Actigraphy" OR "activity monitor" OR "activity tracker" OR acceleromet* OR "pedometer" OR sensewear OR sense-wear OR activPAL OR "PAL 2" OR PAL2 OR IDEEA OR actigraph* OR actiwatch* OR stepwatch OR "actical" OR "activ8" OR "apple watch" OR "googlefit" OR "movemonitor" OR "step activity monitor" OR "StepWatch" OR "axivity" OR "motion logger*" OR motionlogger* OR fitbit OR IPAQ OR "International Physical Activity Questionnaire" OR PASE OR "Physical Activity Scale for the Elderly" OR PACE OR "Physician-based Assessment AND Counselling for Exercise"
Participation	"occupational area*" OR "daily life activities" OR "daily life activities" OR "everyday occupations" OR ADL OR "activities of daily living" OR BADL OR "basic activities of daily living" OR IADL OR "instrumental activities of daily living" OR "self-care" OR "leisure activities" OR "social activities" OR "community activities" OR "community-dwelling" OR "activities at home" OR "social life" OR sleep* OR rest OR "Occupational habit*" OR autonomy OR independence OR "occupational balance" OR "occupational satisfaction" OR "role performance" OR "community participation" OR "social participation" OR "return to work" OR "recovery activities" OR "meaningful activities" OR "participation restriction" OR "participation satisfaction" OR "role performance" OR "community reintegration" OR "community mobility" OR "behavioral mapping" OR ACS OR "activity card sort" OR SIS OR "stroke impact scale" OR BI OR "barthel index" OR FAI OR "frenchay activities index" OR "assessment of life habits" OR LHS OR "london handicap scale" OR LIFE-H OR "assessment of life habits" OR RNLI OR "reintegration to normal living"
Filters	Language: English OR Spanish Publication Years: All years available
Database	**PEDro**
Procedure	Advanced search.
Search (1)	Abstract & Title: Stroke "Physical Activity" Subdiscipline: Neurology
Search (2)	Abstract & Title: Stroke Participation Subdiscipline: Neurology
Filters	Not applicable

2.4. Studies Selection

After removing duplicate records, the initial stage will involve screening studies based on their titles and abstracts, applying the predefined eligibility criteria. Subsequently, the full texts of the selected studies will be thoroughly reviewed and evaluated, again

applying the same eligibility criteria. Studies will be selected at each step by 2 independent researchers (CDA and ABE), and, in case of disagreement, a consensus will be sought by a third researcher (PBL). The EndNote software will be used for reference management [49].

2.5. Evaluation of the Risk of Bias

Two researchers (CDA and PRP) will independently examine the risk of bias of the studies using the Newcastle–Ottawa scale for cohorts or case–control studies [50] and its adaptation to cross-sectional studies [51], while the PEDro scale will be used for clinical trials [52]. A third researcher (PBL) will verify the assessments and resolve discrepancies if any arise.

The Newcastle–Ottawa scale evaluates seven to eight items categorized into three criteria (selection, comparability, and exposure or outcome) with a maximum score of 9 (10 in the case of cross-sectional studies). Articles scoring at least 7 will be classified as "high quality", 4–6 as "fair quality", and less than 4 as "poor quality" [50].

The PEDro scale evaluates eleven items assessing the internal validity and interpretability of the results, where the maximum score is 10 (i.e., one point per item), as the first item is not considered in the final punctuation. Articles scoring at least 6 were considered of "high quality", while a score of 4–5 was considered of "fair quality", and less than 4 points was considered of "poor quality" [52].

Furthermore, to assess reporting bias, an initial step will involve comparing the measures analyzed and presented in the study's protocol, if available. Additionally, the consistency between the variables described in the method section and those reported in the results section of the selected articles will be checked [53].

Finally, a qualitative analysis of the quality of evidence and the strength of recommendations will be conducted using the GRADE approach, similar to previous systematic reviews and meta-analyses of associations [54].

2.6. Data Collection

Two independent researchers (CDA and RGN) will extract data from the selected studies using a standardized data extraction sheet (Supplementary Materials), while a third and fourth researcher (PBL and JBA) will create independent databases, verify that the extracted data match, and resolve any discrepancies.

The following data will be collected: general study information (title, authors, year of publication); sample and subgroup characteristics (sample size, mean age and sex, time since stroke, stroke severity); study characteristics (research design and country); outcome measures (timing of measurement, PA objective device, PA self-reported assessments, participation assessments); intervention, if any; outcome data (PA and participation). In addition, main results, including correlation findings between participation and PA outcomes will be extracted when possible. The results will be grouped and analyzed in relation to the variable of time elapsed since the stroke in the sample. In this way, there will be 2 groups, a sample of participants who have had a stroke less than or equal to 6 months ago and those who have had a stroke more than 6 months ago.

As this review and meta-analysis does not aim to evaluate intervention effectiveness, it is important to clarify that in the case of randomized controlled trials, the treatment arms will be treated as independent cohorts [55]. Consequently, data for each group will be extracted separately.

2.7. Data Synthesis

The data synthesis will be categorized based on the time since stroke, distinguishing between participants who experienced a stroke within 6 months of the study and those who had a stroke more than 6 months ago. This grouping will allow for a comparative analysis of outcomes and potential differences between these two subgroups of stroke survivors.

When there are at least two studies that report a correlation between the same participation and PA outcomes, the weighted summary of correlation coefficients under the

random effects model will be calculated using the Hedges–Olkin method, based on a Fisher Z transformation of the correlation coefficients [56]. Correlations will be considered as 'strong' ($\rho \geq 0.70$), 'moderate' ($0.40 > \rho < 0.69$), 'weak' ($0.10 > \rho < 0.39$), or 'negligible' ($\rho < 0.10$) [57]. If sufficient studies are found, a subgroup analysis will be performed according to areas of participation and/or PA measurement method (i.e., self-reported or objective measures). Additionally, depending on the quality, quantity, and homogeneity of the data obtained in the review, subgroup analyses may be conducted according to variables such as PA intensity or areas of participation. Moreover, age, sex, and/or stroke severity will be included in the analysis as moderators. Heterogeneity between study results will be investigated using I^2 statistics with values > 50% indicating substantial heterogeneity across studies [58]. Publication bias will be examined by using funnel plots and Egger's tests [59]. All analyses will be conducted using STATA v.16.1 (StataCorp, College Station, TX, USA), and alpha will be set at $p < 0.05$.

In cases where the data are not reported directly in an article, up to three attempts will be made to contact the study authors via email to obtain the data. By reaching out to the authors directly, the risk of missing valuable data is minimized, allowing for a more comprehensive analysis. However, if data are finally unavailable, the article will be excluded from the meta-analysis.

2.8. Deviations from PROSPERO Registry

This protocol provides updated information to address the shortcomings identified in the original PROSPERO registry. The registry erroneously indicated that interventions would be evaluated and did not mention the conduct of a meta-analysis. Due to the characteristics of the registry, it is not possible to amend the content beyond updating the review's status. Therefore, this protocol aims to rectify these issues and provide accurate and comprehensive information for the systematic review and meta-analysis that will be conducted.

3. Expected Results

This systematic review aims to address the knowledge gap regarding the relationship between PA and participation levels in people following stroke. The research team anticipate that there will be a positive correlation between PA and participation. We anticipate a higher likelihood of finding a positive correlation in those more than 6 months post-stroke, considering the prolonged recovery process associated with participation [60].

The results of this systematic review will offer a comprehensive synthesis of existing research on the level of PA and participation after a stroke, taking into account the duration since the stroke. This review will also provide potential suggestions for methodological enhancements in future studies that explore the relationship between participation and PA, based on the analysis of methodological quality across all publications to date.

Aligned with the WHO's priority guidelines for health and wellbeing by 2030, secondary prevention focuses on reducing the risk of recurrent strokes [34]. Addressing sedentary lifestyle is crucial, as it is associated with an increased risk of stroke recurrence and impacts an individual's ability to participate in daily activities. By emphasizing the importance of participation and PA, this systematic review with meta-analysis aims to provide a robust foundation for informing clinical practices in neurorehabilitation. By considering the results according to the duration post-stroke, rehabilitation therapies could be better tailored to optimize outcomes and reduce health costs associated with dependence.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/healthcare11152167/s1, Supplementary Materials S1.

Author Contributions: Conceptualization, C.d.D.-A., J.B.-A., A.B.-E., R.G.-N., M.P.L.-R., P.R.-P., V.D.-G., P.B.-L. and N.F.; Methodology, P.R.-P. and P.B.-L.; Validation, A.B.-E. and N.F.; Investigation, C.d.D.-A., J.B.-A. and M.P.L.-R.; Resources, R.G.-N.; Writing—Original Draft Preparation, C.d.D.-A., J.B.-A. and P.B.-L.; Writing—Review & Editing, A.B.-E., P.R.-P., R.G.-N., M.P.L.-R., V.D.-G. and N.F.;

Supervision, P.B.-L.; Project Administration, C.d.D.-A.; Funding Acquisition, V.D.-G. All authors have read and agreed to the published version of the manuscript.

Funding: This work was supported by "Ayudas a Proyectos Internos de Investigación Universidad San Jorge curso 2022–2023" grant number PI 2023 MOTUS-2223024. J.B.-A. is supported by the Grant PIF 2022–2026 from "Gobierno de Aragón", Spain. Authors C.d.D.-A., J.B.-A., A.B.-E., R.G.-N., M.P.L.-R., P.R.-P., V.D.-G. and P.B.-L. are members of the research group MOTUS supported by "Gobierno de Aragón" (n. B60_23D). The funders did not have any role in this study.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: Not applicable.

Acknowledgments: We thank the staff of the library of the Universidad San Jorge for their support in the development of the search strategy for the different databases.

Conflicts of Interest: The authors declare no conflict of interest.

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Artículo: Multidimensional analysis of sedentary behaviour and participation in Spanish stroke survivors (Part&Sed-Stroke): a protocol for a longitudinal multicentre study

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BMJ Open 2023 Feb 15;13(2):e065628
(Editorial: BMJ PUBLISHING GROUP) Q1, JIF:2.4
DOI: 10.1136/bmjopen-2022-065628.

Citar como: *de Diego-Alonso C, Alegre-Ayala J, Buesa A, Blasco-Abadía J, López-Royo MP, Roldán-Pérez P, Giner-Nicolás R; Part&Sed-Stroke Collaborators Group; Güeita-Rodriguez J, Fini NA, Domenech-Garcia V, Bellosta-López P. Multidimensional analysis of sedentary behaviour and participation in Spanish stroke survivors (Part&Sed-Stroke): a protocol for a longitudinal multicentre study. BMJ Open. 2023 Feb 15;13(2):e065628. doi: 10.1136/bmjopen-2022-065628. PMID: 36792320; PMCID: PMC9933767.*

BMJ Open

Multidimensional analysis of sedentary behaviour and participation in Spanish stroke survivors (Part&Sed-Stroke): a protocol for a longitudinal multicentre study

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To cite: de Diego-Alonso C, Alegre-Ayala J, Buesa A, *et al*. Multidimensional analysis of sedentary behaviour and participation in Spanish stroke survivors (Part&Sed-Stroke): a protocol for a longitudinal multicentre study. *BMJ Open* 2023;**13**:e065628. doi:10.1136/bmjopen-2022-065628

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-065628).

Received 13 June 2022
Accepted 16 January 2023

Check for updates

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ABSTRACT

Introduction Stroke survivors usually experience long-lasting functional, emotional and social consequences that might contribute to sedentary behaviour and participation restrictions, which are important targets to address during rehabilitation. However, the trajectory and inter-relationship between these factors are unknown.

Methods and analysis Part&Sed is a research project based on an observational study design with 6 and 12 months of follow-ups in stroke survivors. In addition, a qualitative analysis of the impact of the stroke on the stroke survivor, validation of the Satisfaction with Daily Occupation-Occupational Balance assessment tool and analysis of the reliability of the Fitbit Inspire 2 activity tracker wristband will be carried out. Participants will be chronic stroke survivors with independent walking capacity. Sociodemographic and clinical data, physical activity, ambulation, sleep, quality of life, anxiety and depression, community participation, and occupational satisfaction and balance, as well as data provided by the activity tracker wristband, will be collected. In addition, if the participant has a primary caregiver, the caregiver will also be monitored. A minimum of 130 participants will be recruited to conduct a random-effects multiple regression model. Mixed models for repeated measures will assess the variation over time of the different variables associated with participation and sedentary behaviour. Psychometric properties (eg, internal consistency, construct validity, test–retest reliability) of the Satisfaction with Daily Occupation-Occupational Balance will be determined. Additionally, intraclass correlation coefficients and minimum detectable change will be calculated to assess intrasubject reliability of physical activity and sleep parameters recorded by the Fitbit Inspire 2. The qualitative analysis process will be carried out using the analysis proposed by Giorgi.

Ethics and dissemination The study received ethical approval from the Spanish Regional Ethics Committee 'Comité de Ética de la Investigación de la Comunidad de Aragón' (PI21/333). The results will be made available via peer-reviewed publications, international conferences and official channels.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This large prospective multicentre project examines the multifactorial interaction between physical activity and participation dimensions in Spanish stroke survivors.
⇒ Training sessions on the procedures and administration of the evaluation tools will be conducted to minimise inter-rater variability.
⇒ A novel method for assessing physical activity and sleep parameters in stroke survivors will be explored.
⇒ Stroke survivors with aphasia, no technological knowledge or those living in nursing homes and hospital settings will not be included.
⇒ Physical activity is being monitored by wrist-worn devices which are known to have limitations.

INTRODUCTION

Stroke has an annual global incidence of 12.2 million, being the second leading cause of death in developed countries.[1 2] There is an estimated prevalence of 143 million people living with poststroke disability, thus becoming the third leading cause of disability worldwide and representing the main need for neurorehabilitation.[3] In 2019, Spanish statistics revealed an annual incidence of 61 102 cases and a prevalence of 512 380 people with poststroke disability.[1] Although the most visible poststroke consequences are physical, this population also presents long-lasting cognitive and emotional alterations,[4] as well as restrictions in participation

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in self-care, work, leisure and free time, and social activities.[5–8] Additionally, two-thirds show difficulty in walking independently, which is maintained beyond 3 months after stroke.[9]

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as 'a person's involvement in life situations' and is the product of an interaction between the individual's health condition and contextual factors.[10] Therefore, participation comprehends meaningful activities performed by individuals in their real environment (eg, family or community) that occupy time and give meaning and purpose to their life.[11] Thus, areas of occupation consist of the basic and instrumental activities of daily living, rest and sleep, education, work, playing, leisure and social participation.[12 13]

Physical inactivity and sedentary behaviour are one of the main lifestyle-related risk factors for stroke recurrence.[14] Physical inactivity is defined as an insufficient physical activity level to meet the current recommendations established by WHO[15] and endorsed by the American Heart Association Council.[16] These recommendations consist of achieving 150 min of moderate to vigorous-intensity physical activity per week or 75 min of vigorous-intensity physical activity per week.[17] On the other hand, sedentary behaviour is defined as any waking behaviour characterised by an energy expenditure ≤1.5 metabolic equivalents, while sitting, reclining or lying.[18] If the sedentary behaviour is maintained throughout the day or week while being awake, it can be classified as a sedentary behaviour pattern.[19] Adult populations who comply with WHO recommendations for physical activity show a lower risk of death and developing noncommunicable diseases.[20] However, stroke survivors often report sedentary behaviour most of the day, especially in the afternoon and evening.[21] Additionally, the average number of sleep hours is much higher in stroke survivors than in the healthy population, which is associated with cardiovascular morbidity and mortality.[22]

Regarding the factors that contribute to sedentary lifestyles in the stroke population, it has been observed that inpatient stroke survivors in rehabilitation centres are more sedentary.[23 24] However, those living in the community still do not meet a healthy level of physical activity.[25] On the other hand, the fear of falling is associated with sedentary lifestyles,[26 27] to the extent that stroke survivors reduce activities involving standing or walking by 20% on average.[28] In turn, the intensity and frequency of rehabilitation treatment,[23 29] the place of residence and characteristics of the community,[25] social support,[23] years after stroke,[30] initial stroke severity,[31 32] the type of hemiparesis, greater cognition,[32–34] better endurance and gait speed[32–35] are further examples of contributors to a sedentary lifestyle. Finally, psychosocial factors, such as anxiety, depression and self-efficacy, can play a role.[36 37] This ensemble of factors warrants studies analysing multifactorial relationships and establishing a firm consensus on policies for the rehabilitation of stroke survivors.

Systematic reviews show that poststroke interventions do not impact community participation until several years after stroke[38] and that identifying barriers is key.[39] However, despite the limited evidence regarding the factors that influence participation,[30] having an extensive social network and the ability to walk for a few hundred metres or drive are potential facilitators.[8] Additionally, improvements in physical functioning do not necessarily translate into improved participation in work, domestic, social and leisure activities.[40 41] This could be why stroke survivors feel unsatisfied about not recovering prestroke participation levels in relevant activities, which may be due to their environment, age, acceptance of the new situation or degree of affectation,[42] as well as due to the presence of comorbidities related to cognitive impairment and depressive states.[43]

Therefore, aiming to emphasise social reintegration as a long-term goal,[44] several studies highlight the need to consider other underinvestigated factors, such as the influence of the primary caregiver and the family environment[36]; environmental factors such as climate and daylight hours[33]; or the impact of treatments focusing on health education[45] and the person-centred model.[2]

PART&SED-STROKE PROJECT JUSTIFICATION

The stroke population in Europe, Australia, Canada and the USA is known to have high levels of sedentary lifestyles.[21 25 31 32 46–50] However, there is no solid information about the Spanish population, which would allow the development, as recommended by WHO, of a specific public health plan for the stroke survivors in Spain. For this reason, longitudinal studies are needed to determine the evolution of the level of physical activity after stroke.[44 46]

The assessment tools included in the present protocol have been selected based on the 2018 Cochrane review authored by Lynch *et al*,[51] and by the recommendations of Kwakkel *et al*,[52] and its updates in a 2020 Delphi study.[53] Additionally, other reliable assessment tools are needed to ascertain the amount of sedentary time, assess its effect on health and identify significant predictors of physical activity levels.[14] In this sense, devices with high potential have already been identified at the scientific level,[54 55] and it is known that three or more days, for a minimum of 14 hours/day, are required for accurate monitoring.[56] However, more studies are needed to analyse the potential of new wearable devices to record this physical activity and measure adherence or compliance with physical activity recommendations in the stroke population,[57] as well as to assess their suitability and ease of use in the clinical setting by professionals and patients. Consequently, this protocol will evaluate the Fitbit Inspire 2 activity tracker wristband (Fitbit, San Francisco, California, USA). On the other hand, with the aim of promoting the recovery of participatory life after stroke, it is relevant that clinicians have validated assessment tools for the stroke population on occupational satisfaction.

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The current protocol has also included the Activity Card Sort (ACS), recommended in systematic reviews for the ICF domains of activity and participation in the stroke population.[58 59] Finally, following the recommendations of other studies, other factors such as personal, sociodemographic and psychological factors that may have an impact on mobility in the community have been considered.[33]

Considering that the current goal of neurorehabilitation is to design and personalise physical activity programmes according to the ability, goals and preferences of the stroke survivor, as well as to encourage long-term lifestyle habits,[60] it is warranted to conduct longitudinal studies investigating the trajectory and the inter-relationship between sedentary behaviour and participation in stroke survivors.

Objectives

1. To multidimensionally explore the factors associated with participation and sedentary behaviour in Spanish stroke survivors.
2. To investigate the influence of sedentary behaviour and individual characteristics of the primary caregiver on the participation and sedentary lifestyle of Spanish stroke survivors.
3. To analyse the natural fluctuation of participation, sedentary behaviour and associated factors over 12 months in Spanish stroke survivors.
4. To validate and establish the psychometric properties of the Satisfaction with Daily Occupation-Occupational Balance (SDO-OB) assessment scale for Spanish stroke survivors.
5. To determine the intrasubject reliability values in the short term (1 week) and medium term (6 months) of the Fitbit Inspire 2 activity tracker wristband and evaluate the construct validity of monitoring physical activity and sleep quality using Fitbit Inspire 2 activity tracker wristband versus the scores obtained in the International Physical Activity Questionnaire Short Form (IPAQ-SF) and Sleep Scale from the Medical Outcomes Study (MOS-Sleep) self-reported questionnaires in Spanish stroke survivors.
6. To qualitatively analyse the lived experience of Spanish stroke survivors in terms of barriers and facilitators for the return to physical activity and participation in occupational living, along with the knowledge needed to achieve it.

METHODS

Study design

The present protocol complies with the Strengthening the Reporting of Observational Studies in Epidemiology recommendations,[61] the Consensus-based Standards for the Selection of Health Status Measurement Instruments,[62] the Guidelines for Reporting Reliability and Agreement Studies,[63] the Consolidated Criteria for Reporting Qualitative Research[64] and the Standards for Reporting Qualitative Research.[65]

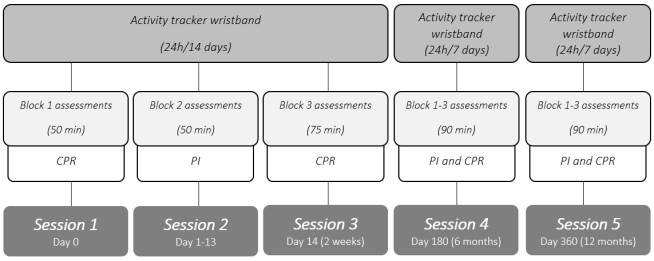


Figure 1 Study timeline design. CPR, collaborating professional researcher; PI, principal investigator.

This study protocol will follow a prospective design with a follow-up of 12 months (figure 1), in which several centres distributed throughout Spain will participate (online supplemental material 1). Specifically, a cross-sectional design will be used to assess factors associated with sedentary behaviours and participation levels in stroke survivors, including the influence of the primary caregiver. The validation and establishment of the psychometric properties of the SDO-OB questionnaire in Spanish stroke survivors will be performed. Additionally, a prospective cohort design will be used to assess the evolution of sedentary and participation behaviours in stroke survivors over time, identifying those factors that may contribute to a modification of these behaviours. Follow-up assessments will be carried out at 6 and 12 months to provide a sufficient time frame in which to appreciate meaningful changes. Finally, the life experience of stroke survivors will be investigated through unstructured in-depth interviews and semistructured interviews, which will be analysed by means of a descriptive phenomenological approach.

Population

The study sample will consist of people of both sexes who have suffered a stroke and reside in Spain. The inclusion criteria will consist of (1) being over 18 years of age; (2) having a history of stroke with a medical diagnosis for more than 6 months, regardless of its aetiology; (3) outpatient living at home; (4) having cognitive and speech ability to perform and understand the tests to be administered and the purpose of the research project (ie, no aphasia and a Mini-Mental Cognitive Test score >24[66]); (5) being able to ambulate with or without aids, which represent an ambulation ability ≥3 in the Functional Ambulatory Category[67] (not applicable for SDO-OB validation); and (6) availability of a mobile phone with Bluetooth and internet connection. The exclusion criteria will be (1) non-acceptance of participation in the research project by the primary caregiver; (2) not tolerating being monitored with an activity tracker wristband; (3) residing in institutions (eg, nursing homes); (4) no commitment to continuity; and (5) a history of more than one symptomatic stroke. Missing evaluation sessions, an existing personal or family situation that interferes with data collection and willingness to discontinue the study were considered withdrawal criteria.

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If the stroke survivor has a primary caregiver, the primary caregiver will be invited to participate in the study. A primary caregiver is defined as a person, either a family member or an employee, who spends more than half of their daily time supporting or caring for the stroke survivor.

Patient and public involvement

Patients or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Contact and recruitment

Centres and health professionals

The collaborators will be composed of health professionals (physiotherapists and occupational therapists) working in institutions, centres and associations, as well as self-employed professionals whose field of action is focused on the neurological rehabilitation of stroke survivors. Specifically, in the first phase, contact will be established via email or telephone with professionals who form part of the research team's network. While in the second phase, general information about the research study will be disseminated through social networks (ie, Twitter and LinkedIn) to increase the number of potential organisations and professionals collaborating. These collaborators will meet the conditions of residing in different parts of Spain, having extensive experience in neurological rehabilitation and currently providing care to stroke survivors.

All those who will show interest in the study will receive a document that includes information on the objective of the study, criteria for the selection of the sample, functions to be carried out that would imply their commitment to participate and a timetable for data collection. If there is continued interest in participating, a first meeting will be held to provide further information and resolve doubts. After this meeting, the centres and professionals will express their willingness to participate. Each participating centre must sign the collaboration agreement, and each professional belonging to these centres must accept the commitment document to participate in the research. These documents will regulate the transfer of the anonymised data collected for research use, as well as the commitments and functions of the institutions and professionals involved.

Participating centres will be instructed in homogenising data collection through videoconference meetings and training sessions. With the aim of facilitating access to information on the study, a secure shared folder has been created in a virtual space containing documents on the study, information sheets for participants, consents, collaboration documents and manuals of procedures to be followed. In addition, the research team will provide and send a minimum of two Fitbit Inspire 2 monitoring wristbands to each collaborating centre.

Stroke survivor participants and primary caregivers

The recruitment process of participants (stroke survivors and their respective caregivers) will be carried out in two phases. First, each of the collaborating centres will be responsible for promoting the existence of the study through their usual internal channels of communication with their users, such as posters, information circulars and posts on social networks. Each potential participant will be given an information sheet about the research project, and any questions they may have regarding the development of the research project and their participation in it will be answered.

Second, those users who voluntarily agree to participate in the study will be assessed by healthcare professionals (occupational therapists and physiotherapists) with training and clinical experience in neurorehabilitation to corroborate compliance with the eligibility criteria. Those who meet the selection criteria will be selected as potential participants and will be asked to sign the informed consent for inclusion in the study. Once the informed consent is signed, they will be assigned an appointment for the first assessment session within approximately 1 week. The same assessors will conduct the assessment sessions at each centre.

Data collection and security measures

Each collaborator will be responsible for collecting part of the data for participants from their centres. The collection of all the data will be supervised and coordinated by the research team, and the principal investigator will be in direct contact with each collaborator to assist with solving any problems that may arise.

In order to maintain security in the process of collecting data from each participant: (1) each collaborator will be assigned an account and password to access the P4Work application where the data collected from each participant in the study are recorded[68]; and (2) each collaborator will be provided with accounts and passwords that must be assigned to each participant (stroke survivor and their main caregiver) to use the Fitbit application.

Only the collaborators at each centre will know the identity of each participant recruited at their centre. In such a way, the research team will have access to anonymised data in both the Fitbit and P4Work applications.

Outcome measures

Sociodemographic data

Sociodemographic data will include age, sex, smoking, educational level, economic level, employment status, height and weight, municipality, type of housing, presence of architectural barriers and home cohabitation.

Clinical data

Clinical data will include information such as age at the time of stroke, type of stroke, damaged cerebral hemisphere, time of evolution, pain experience, other pathologies (including the number of silent or subclinical strokes), current medication, current rehabilitation and hours per week, number of falls in the last 6 months, use of assistive devices, the Barthel Index,[69] the Fall Efficacy

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Scale International (FES-I)[70] and the modified Rankin Scale.[71]

Self-reported physical activity

Self-reported physical activity levels will be evaluated with the IPAQ-SF. The IPAQ-SF is a self-report scale that aims to determine the level of physical activity in the current period (last 7 days) and the time spent sitting down. The final score categorises physical activity levels into low, moderate or high physical activity. The IPAQ is a suitable questionnaire for population-based physical activity monitoring. The IPAQ-SF can be used for physical activity prevalence studies to monitor the population and has demonstrated adequate reliability and validity[72 73] and has been used in previous studies with stroke population.[74]

Self-perceived quality and quantity of sleep

MOS-Sleep will be used to assess the most important dimensions of sleep quantitatively and qualitatively as well as to assess potential sleep disturbances. The tool consists of 12 items whose responses are based on a retrospective assessment over the last 4 weeks.[75] The MOS-Sleep is a suitable and valid questionnaire to obtain information on multiple aspects of sleep quality. The scale has been shown to have good validity and reliability for the assessment of sleep disturbances. It is a sensitive assessment tool for detecting the impact of an illness or medication on the different dimensions of sleep.[76]

Current health status

Current health status will be evaluated with the self-assessed, health-related, quality of life questionnaire 5-Level version of EuroQol-5 Dimension (EQ-5D-5L). The EQ-5D-5L measures quality of life on a 5-component scale, including mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each of these dimensions has five possible answers or levels of severity. In the second part of the questionnaire, respondents are asked to rate their current health status on a scale, where 100 corresponds to 'the best health status you can imagine' and 0 to 'the worst health status you can imagine'. The EQ-5D-5L is a valid and reliable tool for assessing the quality of life.[77]

State of anxiety and depression

The state of anxiety and depression will be evaluated with the Hospital Anxiety and Depression Scale (HADS). The HADS is a 14-item questionnaire consisting of a depression and anxiety subscale with interspersed items. The items are scored on a 4-point Likert scale (0–3) with a total score ranging from 0 to 21 for each subscale, where a higher score indicates greater symptom severity. The HADS is a reliable and valid tool for assessing levels of depression and anxiety[78] and has been used with stroke survivors in previous studies.[79]

Degree of participation

The degree of participation will be assessed using the ACS for the Spanish population. The ACS is a scale that measures self-perceived participation using photographs reflecting everyday activities. The activities are categorised into four domains: instrumental activities, leisure activities with low physical demand, leisure activities with high physical demand and socioeducational activities. It covers eight of the nine domains of participation as defined by the ICF.[10] The final score is the percentage of activities maintained after an illness, which is developed as a quotient between the number of activities carried out before the illness and those carried out at present. The ACS is a reliable and validated tool for measuring the perceived level of participation.[80 81]

Degree of occupational satisfaction and balance

The degree of occupational satisfaction and balance will be assessed with the SDO-OB. The SDO-OB is an interview-based instrument that assesses 13 different occupational items organised into four domains: productivity, leisure or free time, housework and self-care. The SDO-OB assesses the level of participation in an activity, the occupational satisfaction derived from participating in this activity and the perceived occupational balance within each domain. For each item, the interviewer will determine whether there is participation by the person and then indicate the degree of satisfaction from 1 to 7 (1 being extremely dissatisfied and 7 being extremely satisfied). The SDO-OB has good reliability and validity.[82]

Physical mobility tests

The 10-metre walk test (10MWT) will be used to assess walking speed in metres per second. The person will be asked to walk for 10 m while being timed. The comfortable speed for walking over 10 m will be taken three times. The average of the three recordings will be the value of the assessment. The 10MWT is a reliable and validated tool for measuring walking speed.[83]

The 6-minute walk test (6MWT) will be used to assess the distance walked by the participant in 6 min. Standardised guidelines will be followed during the test to give verbal indications concerning the time elapsed and positive reinforcement without any other indications not allowed by the test. The 6MWT is a reliable and valid tool for measuring distance run, endurance and aerobic capacity.[84]

Additionally, walking aids and a modified Borg Index (0–10) will be collected after each test.

Furthermore, physical mobility tests will be performed in all centres under similar standardised conditions. Before signing the collaborating agreement, each centre will ensure sufficient space on its premises to carry out the tests.

Activity tracker wristband

The Fitbit Inspire 2 activity tracker will be used to assess the level of activity throughout 14 days continuously. The device is based on a three-axis accelerometry system that monitors physical activity, number of steps, heart rate, sleep duration and sleep score. The Fitbit wristbands are

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considered a valid and reliable tool for monitoring physical activity and sleep hours,[85 86] which are considered a valid procedure in stroke survivors.[87 88]

Evaluation of caregivers

Sociodemographic data and IPAQ-SF will be collected from primary caregivers during the first interview with study participants who have suffered a stroke. Caregivers will be monitored with the Fitbit activity wristband while the stroke survivor is monitored.

Assessments and temporality

The evaluations will be carried out similarly at three points in time over a 12-month period (ie, baseline, 6 months and 12 months). Each evaluation will be composed of different tests and questionnaires grouped by blocks to avoid saturation of the participants. Specifically, block 1 will be assessed by the collaborators approximately 1 week after recruitment, consisting of sociodemographic data, IPAQ-SF, FES-I, Barthel Index, HADS and EQ-5D-5L. After completing the assessment of block 1, the Fitbit Inspire 2 activity tracker wristband will be linked to the mobile device for 14 days of 24-hour monitoring. Block 2 will be assessed in the settings of collaborator centres approximately 2 weeks after completing block 1, coinciding with the return of the activity tracker wristband, and will consist of the ACS, the 6MWT and the 10MWT. Block 3 will be assessed homogenously in all participants by the principal investigator via teleconference within the period between the blocks 1 and 2, and will consist of clinical data, MOS-Sleep and SDO-OB (figure 1).

One to two weeks after completing the baseline evaluation, a minimum of 50 participants will complete the IPAQ-SF, MOS-Sleep and SDO-OB again. Additionally, during the follow-up period after baseline, a random sample of around 30 participants will participate in unstructured and semistructured interviews as part of the qualitative design.

Qualitative design

A qualitative phenomenological design will be followed based on Husserl's framework.[89] Data collection will be completed when the information obtained in the interviews becomes repetitive.[90] First-person data collection instruments (unstructured and semistructured interviews) and the researcher's field notes will be used simultaneously.[90] Data collection will be conducted in two phases. The first phase of data collection will be conducted through unstructured in-depth interviews. The second phase will be conducted through semistructured interviews based on the analysis of participants' responses from the first phase, together with questions grouped into three research areas: physical activity, participation and health education.

The analysis proposed by Giorgi will be used.[91] The researcher's field notes will complement the analysis of the interviews recorded and transcribed verbatim. MAXQDA 2022 software (Verbi Software, Berlin, Germany) will be used for data analysis.

Different strategies will be followed before and during the data collection process to ensure the methodological rigour and quality of this study (ie, establishing the positioning of the researchers, triangulation, auditing of the material obtained and participant verification).

Monitoring of the methodological quality

Given the multicentric nature of the research study, several mechanisms will be implemented to avoid interobserver bias and reduce random errors as much as possible. First, the assessment protocol comprises measurement instruments with reliable interobserver psychometric characteristics, allowing a standardised data collection. Second, meetings will be held to unify the protocol for the administration of the tools and data collection, establishing a unification of the evaluation criteria for each tool. Third, training sessions on the procedures and administration of the evaluation tools will be conducted both face to face and virtually. Additionally, all collaborators will have written manuals that include these standardised and unified procedures. Finally, the project research team will supervise all procedures and solve any potential issues, sharing the relevant information with all collaborators participating.

Sample size

The sample size has been calculated with G*Power (V.3.1.9.4; Heinrich Heine University, Dusseldorf, Germany) based on the requirements of the most demanding research objective in terms of the number of participants (ie, objective 1). Specifically, after running a priori analysis with an alpha value of 0.05, a power of 80% and expecting a coefficient of multiple determination (r^2) between 0.30 and 0.50, a minimum of 130 participants will be required to perform a random-effects multiple regression model with up to 15 variables. Furthermore, a sample size higher than 73 participants during follow-ups will be sufficient to perform a mixed model for repeated measures with a power of 80% and an alpha error of 0.05 to detect a small to medium standardised mean difference (ie, f=0.15) and expecting at least a moderate correlation among repeated measures (ie, r=0.5).

Statistical analysis

The results will be presented in tables and graphs by presenting the mean and SD, or the median and IQR values, depending on the normality of the data.

Random-effects multiple regression models will be used to examine the factors associated with the stroke survivor's participation and sedentary behaviour, including the sedentary behaviour and individual characteristics of the primary caregiver.

Mixed models for repeated measures will be used to assess the variation over time of the different variables associated with participation and sedentary behaviour.

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In the validation process of the SDO-OB in the Spanish stroke survivors, Cronbach's alpha statistic will be used to test internal consistency and intraclass correlation coefficients to assess test–retest reliability. In addition, Spearman's rank correlation will be used to assess the construct validity of the SDO-OB compared with EQ-5D-5L and ACS.

Pearson's correlations will be used to assess the construct validity of the activity tracker wearable compared with self-reported measures. Furthermore, intraclass correlation coefficients with a 95% CI, the SE of measurement and minimum detectable change will be calculated to assess intrasubject reliability of physical activity and sleep parameters recorded by the Fitbit Inspire 2 collected during two consecutive weeks.

Limitations

This project has some limitations. First, our population does not include stroke survivors with aphasia, an important group who are often excluded from research. Additionally, our population does not include those with limited technical knowledge or people living in nursing homes. Therefore, the generalisability of the results of this study will be limited. This study will not provide insights into physical activity and participation in the acute and subacute phases of stroke recovery, as it only commences in the chronic phase. Finally, physical activity is being monitored by wrist-worn devices which are known to have limitations.[87]

Ethics and confidentiality

The study protocol has been designed following the Helsinki statement and approved by the Spanish Regional Ethics Committee 'Comité de Ética de la Investigación de la Comunidad de Aragón' (PI21/333). All patients will receive an information sheet explaining the purpose of the study and the tests and assessments that will be performed if they agree to participate in the study. In addition, subjects will sign the informed consent form once they have agreed to participate in the study. There will be no financial compensation of any kind to the participants in this project.

Dissemination

Any deviation from the protocol will be presented and justified at the time of publication of the results. Regardless of the outcome, the results will be made available via peer-reviewed publications in open-source journals and relevant international conferences within the field of health and behavioural sciences or neurology, among others.

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Acknowledgements We thank all the collaborating centres involved in the recruitment of study participants: ADACECO (Asociación de Daño Cerebral de A Coruña) in A Coruña; AENO (Asociación de Enfermos Neurológicos Oscense) in Huesca; AGREDACE (Asociación de Daño Cerebral Adquirido de Granada) in Granada; AIDA (Asociación de Ictus de Aragón) in Zaragoza; ASPAYM (Asociación de personas con lesión medular y otras discapacidades física) in Burgos; CENNER (Centro de NeuroRehabilitación, Nutrición y Fisioterapia) in Pamplona; Centro de neurorrehabilitación (Clínica de Rehabilitación Neurológica Sant Cugat) in San Cugat del Valles; CIRON (Centro Integral de Rehabilitación ON) in Valladolid; freelance physiotherapist in Madrid and Sanlúcar de Barrameda; Fundación Pita López (Centro de Neurorehabilitación de Daño Cerebral Adquirido) in Madrid; Grupo 5 CIAN Navarra (Centro Integral de Atención Neurorehabilitadora) in Pamplona; Grupo 5 CIAN Zaragoza (Centro Integral de Atención Neurorehabilitadora) in Zaragoza; Hospital Provincial Sagrado Corazón de Jesús in Huesca; Hospital Universitario San Jorge in Huesca; INEURO (Neurorrehabilitación y Atención al Neurodesarrollo) in Sevilla; NEUFIS (Centro de Fisioterapia y Neurorrehabilitación) in Vitoria; NEURAXIS (Rehabilitación Neurológica y Desarrollo Infantil) in Ferrol; NEUROESPLUGUES (Centre de Rehabilitació Neurològica) in Esplugues de Llobregat; Rehabilitación El Carmen in Zaragoza.

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Contributors CdD-A and PB-L conceived and planned the project. CdD-A, PB-L, JA-A and VD-G, with the collaboration of the rest of the authors, contributed to the design of the study protocol. CdD-A, AB, JG-R and PR-P contributed to the qualitative study design. CdD-A, PB-L, JB-A, RG-N, MPL-R and VD-G contributed to the reliability study design. CdD-A led the recruitment of participating centres and coordination of the professional collaborators. 'Part&Sed collaborators' contributed to checking and testing the protocol design and will conduct the data collection. CdD-A, PB-L, AB, JB-A, JG-R, VD-G and NAF contributed to writing the article. All authors have read and approved the final manuscript.

Funding This work was supported by 'Ayudas a Proyectos Internos de Investigación Universidad San Jorge curso 2021–2022' (grant number: 2122037) and 'Ayudas a Proyectos Internos de Investigación Universidad San Jorge curso 2022–2023' (grant number: 2122037). PB-L is supported by Grant FPU19/05237 and JB-A by Grant PIF 2022-2026 from 'Gobierno de Aragón'.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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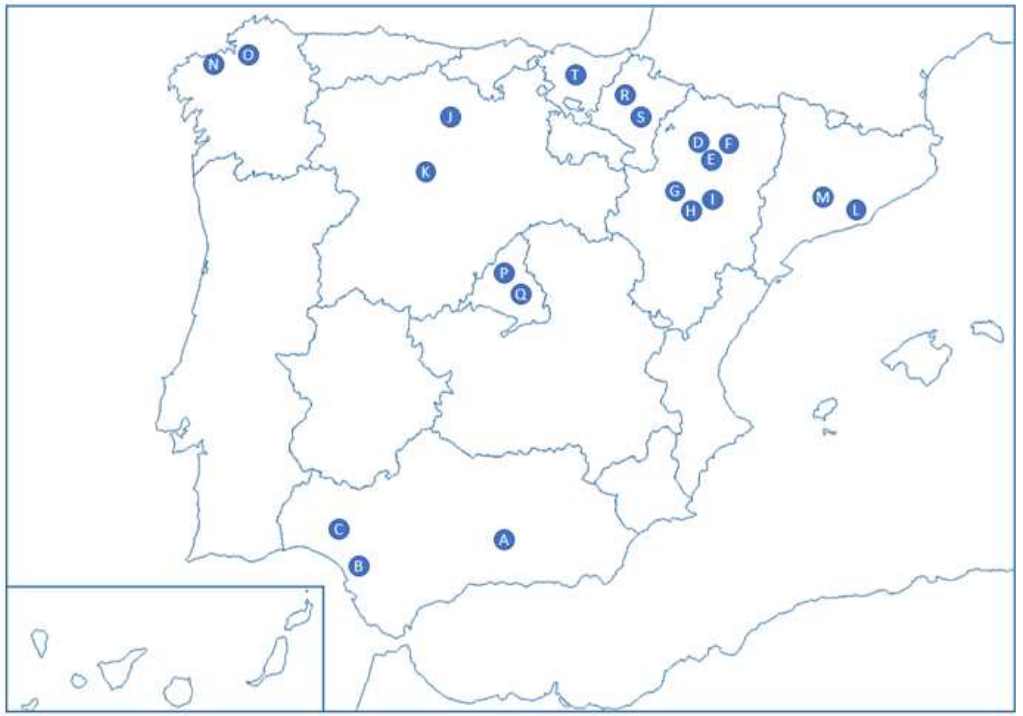
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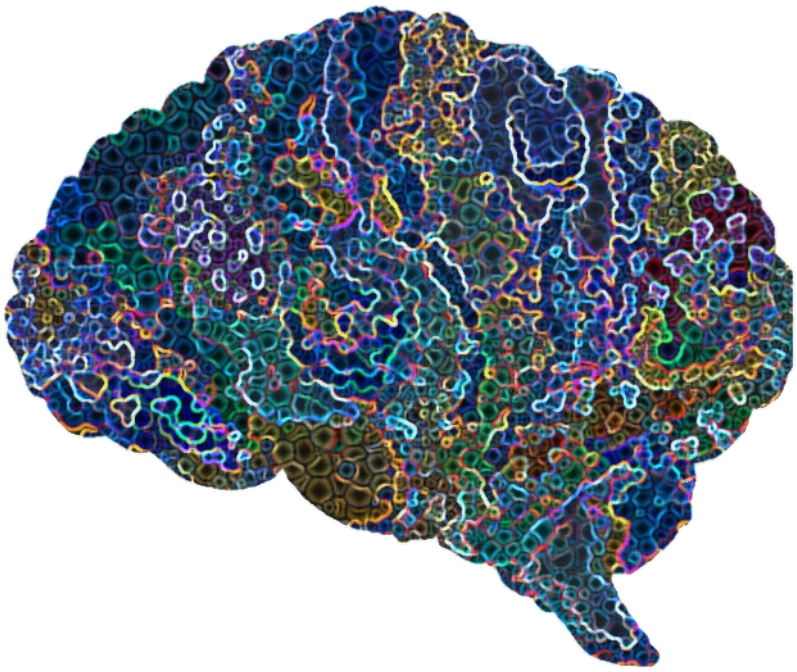
SPAIN REGION	CITY	CENTER NAME
Andalucía	Granada	AGREDACE (A)
Andalucía	San Lucar de barrameda	Freelance Physiotherapist (B)
Andalucía	Sevilla	INEURO (C)
Aragón	Huesca	AENO (D)
Aragón	Huesca	Hospital Provincial Sagrado Corazón de Jesús (E)
Aragón	Huesca	Hospital Universitario San Jorge (F)
Aragón	Zaragoza	AIDA (G)
Aragón	Zaragoza	Grupo 5 CIAN Zaragoza (H)
Aragón	Zaragoza	Rehabilitación El Carmen (I)
Castilla y León	Burgos	ASPAYM (J)
Castilla y León	Valladolid	CIRON (K)
Cataluña	Esplugues de Llobregat	NeuroEsplugues (L)
Cataluña	San Cugat del Vallés	Clínica de neurorrehabilitación (M)
Galicia	A Coruña	ADACECO (N)
Galicia	Ferrol	NEURAXIS (O)
Madrid	Collado Villalba	Fundación Pita López (P)
Madrid	Madrid	Freelance Physiotherapist (Q)
Navarra	Pamplona	Grupo 5 CIAN Navarra (R)
Navarra	Pamplona	CENNER (S)
Pais Vasco	Vitoria	NEUFIS (T)



Supplementary material 1. List of participating centres in relation to their geographical location in Spain.

UNIVERSIDAD SAN JORGE

Facultad de Ciencias de la Salud



Cristina de Diego Alonso, 2024